The LifeBio Pilot Project

A Final Report and Project Summary

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Executive Summary

The LifeBio pilot study in Ohio was conducted to evaluate the effectiveness and impact of the LifeBio program (referred to as "LifeBio"), a non-pharmacological intervention to facilitate person-centered care by helping nursing home (NH) staff better understand residents through their personal life stories. Interventions such as LifeBio can play an important role in addressing person-centered care as a key metric in the Centers for Medicare & Medicaid Services' *National Nursing Home Quality Improvement Campaign.* NHs in two counties in Ohio participated in a pilot study to develop life story books, one-page Snapshots, and Action Plans for their residents, train staff to use them to support individualized care, and evaluate their impact. Life story information was collected from residents and/or their family members by trained community volunteers, interns and staff. The partner organizations were Benjamin Rose Institute on Aging (BRIA), LifeBio Inc., Universal Health Care Action Network (UHCAN Ohio) and the Government Resource Center (GRC).

BRIA conducted an evaluation of the LifeBio program from the perspective of NH residents, staff, family members/legal guardians, and volunteers who gathered resident life story information, and examined the feasibility of using volunteers to conduct life story interviews. For residents, the project aimed to measure the impact of life story work through in-person interviews covering satisfaction with care; perceived usefulness of creating life stories; physical health, mental health, and quality of life. The project also surveyed family members to evaluate the impact of LifeBio on family satisfaction with care and their perceived usefulness of creating residents' life stories. For staff, evaluators focused on job satisfaction, the perceived usefulness of knowing residents' life stories, and the feasibility of utilizing volunteers to collect residents' life story information. Finally, volunteer outcomes examined were satisfaction with the experience of collecting life stories and their perceived usefulness of creating them.

The project teams recruited 16 NHs, four in Ashtabula County, and 12 in Cuyahoga County that varied in terms of rural/urban/suburban location, size, auspice, and quality ratings. Their size ranged from 61 to 165 beds, and their Nursing Home Compare overall quality star ratings ranged from 1 to 5. In terms of auspice, three sites were non-profit NHs and 13 were for-profit. The project teams worked with NH site liaisons to identify eligible residents for recruitment, mail surveys to family members, use paper-and-pencil tests with staff, and coordinate scheduling of on-site resident interviews. Sites were paid $1,000 as a stipend.

For residents, BRIA researchers conducted three in-person interviews at baseline, immediately after the life story interview, and 30 days following the delivery of their life story books with 186 residents. Resident eligibility criteria included being a Medicaid beneficiary, 60 years or older, long-stay (90 days or more), and not severely cognitively impaired. Results indicated high levels of satisfaction with NH care over time, but no significant change in mean levels of satisfaction. Although no significant differences were noted in the perceived usefulness of life stories over time, more than 60% responded positively to statements about the importance of staff knowing their life stories, and more than 80% of residents reported positive experiences and enjoyment with various aspects the program, The majority of residents reported that they intended to share their life story materials with family and friends (90%) and staff at the NH (62%), and nearly half had shared this information in the month after receiving their life story books. Roughly 52% of residents reported mild to severe symptoms of depression, and a significant decrease in depressive symptomatology

was observed following participation in the LifeBio intervention. No significant differences were reported in assessments of physical health or quality of life following the LifeBio intervention, though self-ratings were relatively high on these measures which reduced the ability to detect treatment effects.

Later, the program was offered to all residents (irrespective of eligibility criteria), and those who participated reported positive experiences based on measures of satisfaction.

Ninety-two NH staff members were surveyed during a LifeBio training session prior to the intervention and completed follow-up surveys roughly 30 days after the resident life story materials were delivered to the NH where they worked. Staff members reported a significant improvement over time in the way management and staff worked together, and in their perceptions of the importance of knowing residents' life stories. The majority of staff (85%) had positive experiences with the LifeBio program and responded that the life story books, one-page Snapshots, and Action Plans that were produced for each resident were of excellent quality; more than 76% reported using them in care plans approximately 30 days after books were delivered, and 86% would recommend the program to other NHs. Administrators and admissions staff reported that it would be feasible to collect life history interview at intake, that volunteers would help with collecting life stories, but there was less enthusiasm to pay for this as a regular activity.

Thirty family members, friends or relatives who were most involved in the care of residents completed surveys mailed by nursing home liaisons prior to the residents' life story interviews, and again 30 days after the life story books were delivered to the NH. Family members reported high levels of overall satisfaction with care in the NHs, but no significant change was reported over time. However, family members reported a significant decrease over time in their perceptions of the importance of life stories in improving care for their relatives.

Volunteers completed post-test surveys electronically or by mail at the conclusion of the project. Approximately 31 volunteers were trained to collect life stories, but only 14 conducted resident life story interviews and 11 completed a survey. Volunteers reported high satisfaction with the training to collect life stories, the program's materials, the experience conducting the interviews, and positive perceptions of the usefulness of life story information.

The project faced challenges due to administrative delays which impacted the recruitment and retention of volunteers, the study design and timeframes for data collection, program fidelity, and NH participation. This led to modifications to staff training, use of additional staff and interns to collect life stories, and changes in research design and protocols that allowed the project team to accommodate tight timelines and deliver the products.

The overall findings indicate the majority of residents and staff who participated in the program found it to be a positive experience, producing significant improvement in depression symptoms, and supporting staff to provide individualized care. Life story work can be useful to residents and staff in delivering better person-centered care, may be a source of pride for those residents who enjoy sharing a life story book with others in a NH, may help to reduce depression by promoting better engagement between residents and staff, and has feasibility as a regular activity from the perspective of senior NH management. Developing a larger study that addresses the limitations experienced in this pilot project, including adherence to the original rigorous research design and

timeline, and following up with staff over a longer period after life story books have been delivered in a NH, will help determine the extent to which the findings can be generalized.

Section I. BRIA Evaluation of LifeBio Pilot Project

Overview of Project

The LifeBio pilot study was conducted to evaluate the effectiveness and impact of the LifeBio program (referred to throughout as "LifeBio"), a low-risk, non-invasive, non-pharmacological nursing home intervention. LifeBio is designed to facilitate person-centered care by helping nursing home (NH) staff better understand residents through their life stories.

Recent evidence suggests that life story work in general may help staff develop a deeper understanding of residents' backgrounds and increase resident satisfaction with care (Grøndahl, Persenius, Bååth, & Helgesen, 2017). More widely, it can also enhance relationships among staff, residents, and family members because the life stories can enable resident identities and preferences to be incorporated into everyday care regimens (McKeown, Clarke, Ingleton, Ryan, & Repper, 2010; McKeown, Clarke, & Repper, 2006). For example, staff can use information from life stories to improve care, facilitate conversations with residents, and establish stronger therapeutic relationships with care recipients (Kellett, Moyle, McAllister, King, & Gallagher, 2010; McKinney, 2017). Thus, interventions such as LifeBio can play an important role in addressing person-centered care, a key metric in the Centers for Medicare & Medicaid Services' *National Nursing Home Quality Improvement Campaign*.

In this LifeBio pilot project, NHs in two counties in Ohio participated in a program to develop life story books, one-page Snapshots, and Action Plans for their residents. An outreach strategy to recruit Medicaid-eligible nursing home residents to participate in the LifeBio pilot project was developed and implemented by BRIA, in collaboration with GRC, ODM, LifeBio, Inc., and UHCAN Ohio. BRIA conducted an evaluation of the impact of LifeBio from the perspective of residents, staff, family members/legal guardians, and volunteers who gathered resident life story information, and examined the feasibility of using volunteers to conduct life story interviews if the program was to be expanded to all Ohio NHs. Findings from the evaluation may assist Ohio policymakers by providing preliminary evidence of the importance of life story work with Medicaid residents, as well as the feasibility and sustainability of implementing the program as a quality improvement project in NHs across the state.

Background Literature

Although NHs have traditionally employed a medical model of institutionalized care, a shift toward more home-like environments, with attention to quality of life and satisfaction from the resident perspective, is at the heart of the culture change movement in long-term care (White-Chu, Graves, Godfrey, Bonner, & Sloane, 2009). The core philosophy of this movement is to provide care in a way that respects and honors the individuality, autonomy, preferences, personal history, and capabilities of residents (Entwistle & Watt, 2013). This is also important for residents with cognitive impairment such as dementia, so that care reaffirms the self and personhood (Fazio, Pace, Flinner, & Kallmyer, 2018).

Culture change initiatives focus on continuous quality improvement to NH environments and staff practices to incorporate resident preferences for care, increase satisfaction, strengthen relationships, encourage empowerment, and foster collaborative decision-making between residents and staff (Koren, 2010). Preliminary evidence suggests these changes in NH culture can positively influence quality of care and relationships between residents and staff (Grabowski et al., 2014; Hartmann et al., 2018; Li & Porock, 2014; Miller, Lepore, Lima, Shield, & Tyler, 2014; Zimmerman et al., 2015).

In practice, gathering and using resident life stories as a component of culture change can promote person-centered care in various ways. Life story work is a multi-faceted approach with many forms and mediums for the collection, representation, and sharing of life stories (Kindell, Burrow, Wilkinson, & Keady, 2014). Although methods vary, these interventions generally take a biographic approach to care, assist caregivers in "seeing the person behind the patient," and provide context for understanding current behaviors (Clarke, Hanson, & Ross, 2003). Preliminary quantitative and qualitative evidence suggests that life story work can have positive influences on residents' psychosocial outcomes, such as overall quality of life, depression, enhanced autobiographical memory; and improved relationships with formal and informal caregivers and family members (Elfrink, Zuidema, Kunz, & Westerhof, 2018; Morgan & Woods, 2010; Subramaniam, Woods, & Whitaker, 2014). However, inconsistent application, measurement variations, weak study designs, and inadequate reporting of study information make it difficult to generalize findings across studies.

LifeBio Inc. is an Ohio-based company specializing in reminiscence interventions for senior living and health care settings. To date, studies evaluating the LifeBio intervention are primarily anecdotal. The intervention has been implemented in NHs and senior-care facilitates to provide individualized care, and there is preliminary evidence of a positive impact on mood and quality of life among seniors and early stage dementia patients (Smith et al. 2017). The purpose of this project was to evaluate the impact of the LifeBio program on improving quality of care from the perspective of NH residents, staff, family members, and volunteers who gathered the residents' life stories. Another goal of the program was to test the feasibility of using volunteers to gather residents' life stories as a method of sustaining and expanding this type of quality improvement program to other NHs in Ohio.

Research Questions

The following research questions are addressed in this evaluation.

Residents. What is the impact of the LifeBio program on NH residents in terms of: 1) satisfaction with care; 2) perceived usefulness of creating their life stories; and 3) physical health, emotional health, depression, and quality of life?

Staff. What is the impact of the LifeBio program on NH staff members': 1) job satisfaction and 2) perceived usefulness of creating residents' personal life stories? From the perspective of administrators and admissions staff: 1) How feasible would it be to make LifeBio a regular activity/program offered to NH residents?

Family members, relatives, and legal guardians. What is the impact of the LifeBio program on family members': 1) satisfaction with care provided by the NH and 2) perceived usefulness of creating residents' personal life stories?

Volunteers (who gathered residents' life stories). What is the impact of the LifeBio program on volunteers': 1) satisfaction with participating in the program and 2) perceived usefulness of creating residents' personal life stories?

Description of Intervention – The LifeBio Program

The LifeBio program aims to enhance person-centered care by improving the understanding and relationship of older adults with the staff who care for them. It does so by creating life story books for older adults, a one-page Snapshot (summary), and an Action Plan that staff can use for care planning. Topics in the life stories include family history, people that made a difference, childhood memories, hobbies and interests, work history, historical events in adulthood, and life lessons and beliefs.

In this project, life story information was collected from residents and/or their family members by trained community volunteers, UHCAN Ohio staff, LifeBio, Inc. staff and interns, and a NH staff member. Interviewers participated in a three-hour training using a training manual developed by LifeBio, Inc. They practiced conducting interviews using the About Me Journal guide. The interview protocol started with basic questions about residents' hometowns to "break the ice" prior to delving into details such as information about family members, school and work experiences, accomplishments, goals, activities, preferences and beliefs. Interviewers were also encouraged to collect pictures and memorabilia and take a photograph of the resident (with the resident's permission).

The interview with each resident lasted approximately one hour. In a few cases, families provided further information to the interviewers over the phone. Staff and family members could also supply additional information via the LifeBio, Inc. web portal. The information from the "About Me Journal" and the web portal was used by writers and editors at LifeBio, Inc. to develop life story books, a one-page Snapshot to display in or outside the resident's room, and a one-page Action Plan to be used by NH staff to provide person-centered care (see Appendix A for additional information about these resources).

To prepare staff members on how to best utilize the information from the resident life stories and Snapshots, LifeBio, Inc. conducted an hour-long training at each of the participating NHs that included instructions on how to use the Snapshots and Action Plans. Continuing Education Units (CEUs) were provided to social workers and activity staff[1]. Nurse aides received a certificate of attendance.

After all life story books, Snapshots, and Action Plans were delivered to a NH, LifeBio, Inc. conducted a second staff training session. The follow-up training focused on using the information to provide better care, learn one new thing about a resident from the book, and increase engagement with them. The goal was to encourage staff to use this information in interactions with residents to enhance person-centered care and build deeper relationships with them.

[1] In Ohio, nurses can use some social work CEUs for their continuing education.

Methods

Site Selection

Data on the census, auspice, quality ratings, and other NH characteristics were downloaded from the Ohio Governor's Office of Health Transformation and the Centers for Medicare & Medicaid Services (CMS) Nursing Home Compare websites (Ohio Governor's Office of Health Transformation, 2017; Centers for Medicare & Medicaid Services, 2017). NHs in Cuyahoga and Ashtabula Counties were chosen to ensure a mix of urban and rural sites; those with large censuses and high rates of Medicaid utilization (+50%) were targeted first. Pairs of sites were originally grouped on auspice (for-profit versus non-profit) and CMS quality ratings to assist with developing a list of matched intervention and wait-list control NH sites. However, due to compressed timelines and unexpected project delays once the project began, the wait-list control design was changed to a pre-post study design.

Sites were initially contacted for recruitment into the program via a letter to the NH administrator describing the project and its evaluation, along with a summary of the LifeBio program and an "interest in participation form" that requested the name and title of a site liaison. Subsequently, potential sites received follow-up e-mails and phone calls to gauge interest in participation. Initial meetings of 60-90 minutes were scheduled with administrators and liaisons at sites that returned the "interest in participation form" to explain study protocols and to discuss the scheduling of interviews and logistics of data collection. Liaisons were also guided on how to assist with recruiting study participants. Additional meetings were often held between BRIA staff and liaisons to review study protocols and recruitment materials to ensure that study protocols were being followed with fidelity.

NHs were recruited on a staggered basis to manage workloads for conducting the evaluation and the life story interviews. Each participating NH resident received a free resident life story book and one-page Snapshot. Participating NHs received Action Plans for each participating resident and a $1,000 stipend.

Study Design, Data Sources and Measures

The LifeBio project utilized different study designs, data sources, and measures for each type of participant as described below.

Residents. A longitudinal study design was used to conduct in-person research interviews with residents at three different points in time. A baseline interview was conducted prior to a resident being interviewed for their life story (Time 1 [T1]); a brief post-test was conducted immediately following the life story interview with a resident (Time 2 [T2]); and a follow-up interview was conducted approximately one month after most life story books and Snapshots were delivered to their NH (Time 3 [T3]).

Baseline (T1) and follow-up (T3) interviews with residents were conducted by BRIA researchers and included measures covering the Brief Interview of Mental Status (BIMS), social relationships,

depression, activities of daily living, satisfaction with NH care, quality of life, and satisfaction with care in the NH at T1 and T3. For the complete contents of the resident measures, please refer to Appendix B, pages B1-B13.

Quality of life was assessed using five items, beginning with a global measure asking residents to rate their overall quality of life from "very bad" (1) to "very good" (5). Residents' were also asked about their physical and emotional health, rating each of these as "poor" (1), "fair", "good", "very good" or "excellent" (5). Residents' perceived usefulness of life stories was also measured with items asking residents about the usefulness of their life story; response choices ranged from "Strongly disagree" (1) to "Strongly agree" (5). The items asked residents if it is important for staff to know their life story and if staff are interested in their life story.

Scales were created for several measures in the T1 and T3 surveys. These are:

i) *BIMS:* Comprised of 7 items testing the repetition of words, temporal orientation and short-term recall. Scores range from 0 – 15 with 0-7 indicating severe cognitive impairment, 8-12 indicating moderate impairment, and 13 – 15 indicating no impairment. Although the alpha level was low with the LifeBio pilot study population (Cronbach's alpha = .51), in prior research, it was found to be a reliable measure, with a Cronbach's alpha = .77 (Mansbach et al., 2014); also, the scale is taken directly from the MDS 3.0, which NHs are required to complete for reimbursement.

ii) *Activities of Daily Living (ADLs):* Comprised of 6 items asking residents about their level of assistance with bathing, eating, dressing, grooming, getting in and out of bed, and walking. Response choices range from "without any help" (1) to "Completely unable" (3). Total scores range from 6-18 with higher scores indicating a higher level of functional impairment (Cronbach's alpha = .81).

iii) *Patient Health Questionnaire:* Comprised of 8 items to determine depressive symptomatology in the past two weeks. Response choices range from "not at all" (0) to "nearly every day" (3) and total scores range from 0-24 with higher scores indicating higher levels of depressive symptoms (Cronbach's alpha =.79).

iv) *Older People's Quality of Life (OPQOL)*: Comprised of 4 items regarding quality of life. Response choices range from "Strongly agree" (5) to "Strongly disagree" (0) and total scores range from 0 – 20 (Cronbach's alpha = .61).

v) *Satisfaction with Care in the NH:* Comprised of 8 items that assess satisfaction with NH care, including participation in meaningful activities, resident care preferences being followed by staff, staff knowledge of what residents like and dislike, gentle treatment from staff, care being provided in the way the resident wants, staff going above and beyond to give residents a good life, residents reporting being friends with someone in the NH, and recommending the home to their family or friends. Response choices are "generally yes" (1) or "generally no" (0). Total scores range from 0-8 (Cronbach's alpha = .79).

The T2 survey, which was very short, was comprised of seven questions regarding *residents' experiences with participating in the life story interview and its perceived impact.* These data were

collected by volunteers or LifeBio, Inc. staff and interns who conducted the life story interviews. The same seven questions from the T2 survey were included again in the T3 survey, and BRIA researchers collected these data. A scale for these items was not created because researchers believed it was important to examine all the items pertaining to their perception of participating in the LifeBio program individually.

In addition to interview data, the most recent resident data available from the Minimum Data Set (MDS) were obtained from ODM. These data provided a profile of participating residents, and included measures such as demographic characteristics, length of stay, emotional health, and medications.

Staff. A pre-post study design was utilized with staff. A paper survey was distributed at baseline (T1) prior to staff training on how the LifeBio program would be implemented in NHs. Post-test surveys were mailed or distributed to staff approximately 30 days after the majority of resident life story books were delivered to their NH.

Baseline (T1) questions for staff addressed demographics, job satisfaction, job turnover, and perceived usefulness of life stories. For the complete contents of the staff measures, refer to Appendix B, pages B14-B20.

Job Satisfaction was measured by 9 items with response choices ranging from "very dissatisfied" (1) to "very satisfied" (4). A tenth item asked whether or not the respondent would recommend that a friend or family member take a job at their NH.

Administrators and admissions staff were asked supplemental questions on the *feasibility and sustainability of implementing the LifeBio program* in their NH after the project ended. A scale was not created of these items since BRIA staff believed it was important to examine the items on feasibility and sustainability of the program individually.

Staff T2 surveys included several questions on the *perceived usefulness of the life story program*; these items were analyzed individually.

Family Members. A pre-post study design was utilized for family members; a paper survey was mailed to them following a similar T1 and T2 timeline as described for staff.

Measures for family/legal guardians at baseline (T1) and post-test (T2) included questions on demographics; frequency of visitation; and family satisfaction with care at the NH. For the complete contents of the measures in the family survey, refer to Appendix B, pages B21-B26.

Scales were created for the following measures:

Family satisfaction with NH care for the resident was comprised of 5 items that assessed satisfaction in engagement in meaningful activities, staff respecting resident preferences, staff knowledge of what residents like and dislike, staff inclination to go above and beyond to give residents a good life, and likelihood of recommending the NH to family or friends. Response

choices ranged from "definitely no" (1) to "definitely yes" (4). Total scores range from 5-20 (Cronbach's alpha = .64).

The perceived usefulness of resident life stories, with response choices from "strongly disagree" (1) to "strongly agree" (5) comprised an additive scale with three items. Scores ranged from 3 to 15, with higher scores indicating higher perceived usefulness of life story information (Cronbach's alpha = .74).

Volunteers. A post-test study design was used for surveys after completion of the project. Volunteers were offered the option to complete an online or a mailed survey. The volunteer survey included questions covering demographics, experiences with the program, perceived usefulness of life stories, and satisfaction with their experience in the NHs. No scales were created for measures in the volunteer survey. For the complete contents of the measures in the volunteer survey, please refer to Appendix B, pages B27- B33.

Selection of Study Participants

Residents. The population of interest in this study was long-stay (more than 90 days), Medicaid-enrolled, English-speaking NH residents who were age 60 or older. Long-stay residents were recruited, as they could potentially benefit more from an intervention involving life story work due to their extended residence and consistent interactions with staff in the same NH, compared to short-stay, rehabilitation, or post-acute care residents. In addition, investigators targeted residents who scored 8-15 on the BIMS, excluding residents with severe cognitive impairment who could not participate in research interviews. LifeBio materials were only available in English, so non-English speaking residents could not be included in this this pilot study. Residents who lived in locked behavioral health units were also excluded, due to difficulties with BRIA researchers gaining access to them.

At the conclusion of the evaluation, a second wave of the LifeBio intervention was offered to residents of the participating NHs who did not meet these eligibility criteria to participate in the evaluation (see Section IV on Opening up the LifeBio Program to all NH Residents). **Staff.** Key staff, including nurse aides, activities staff, administrators and assistant administrators, social workers, and admissions coordinators were targeted for participation in the project. Frontline staff regularly interact with residents and could use life story information to enhance person-centered care in residents' daily routines. Administrators and admissions staff were invited to participate due to their knowledge of the NH's operations and to obtain their perspective on the feasibility and acceptability of incorporating questions about a resident's life story in the admissions process, and to examine their openness to sustaining the program after the project ended. However, training on the use of life story information was open to all employees at participating sites.

Family and Legal Guardians. Protocols for the recruitment of family members and legal guardians were similar to those used by the Ohio NH Family Satisfaction Survey to select each resident's 'most involved' family member or friend[2]. Liaisons were asked to identify the 'most

[2] The NH Family Satisfaction Surveys were initiated in 2000 to examine the family perspective of care in NHs. Ohio was the first state in the nation to implement both resident and family NH satisfaction surveys as a means of examining quality of care in NHs. The surveys are now being

involved' family member or friend who visited the resident most often, talked to staff about the resident, participated in care planning, attended family council meetings, and helped take care of the resident (Ejaz, Straker, Fox, & Swami, 2003). However, if a resident had a legal guardian, the guardian was always selected as the 'most involved' family member.

Volunteers. Volunteers were recruited from a variety of local organizations such as churches, community groups, and senior centers in Cuyahoga and Ashtabula Counties, primarily by UHCAN Ohio, although BRIA staff also helped make contacts with community agencies. The volunteers were all adults and received training by UHCAN Ohio using LifeBio, Inc. materials to conduct NH resident life story interviews. When enough volunteers could not be recruited for a particular NH, LifeBio, Inc. staff and interns, and others (e.g., UHCAN Ohio staff, and a NH activity staff) conducted the life story interviews.

Study Procedures

Residents. After the initial site visit with project staff, the site liaison created an internal list of eligible participants based on the eligibility criteria described earlier, identified those with legal guardians, and selected the 'most involved family member' for residents without legal guardians. The site liaison first distributed introductory flyers developed by BRIA that described the project to eligible residents without legal guardians. These residents had the option to check a box on the flyer to indicate they did not want their name or information released to anyone from the LifeBio project. This process was used to comply with HIPAA regulations prohibiting the release of resident information to third parties without the resident's consent.

About a week after the flyers were distributed to residents without legal guardians, site liaisons checked in with them to gather the flyers. Subsequently, liaisons sent BRIA an encrypted list of residents who had not objected to having their names released.

In the case of residents with legal guardians, BRIA staff did not approach these residents/wards until consent to participate was received from their legal guardians (please refer to the section below that describes procedures used for legal guardians).

Family and Legal Guardians. Site liaisons mailed evaluation packets prepared by BRIA to the 'most involved family member' for residents without legal guardians because NHs could not release family member names and contact information to BRIA directly without their permission. These mailings contained an (1) introductory letter explaining the project; (2) consent form; (3) T1 family survey; (4) postage-paid envelope addressed to BRIA to return the consent form and T1 survey; and (5) information indicating how they could contribute to their relative's life story book.

For residents with legal guardians, site liaisons sent the legal guardians a similar evaluation packet prepared by BRIA that included a consent form and a T1 family/guardian survey. An important difference in the consent form included in this packet was that legal guardians had two separate boxes to check for agreeing to participate in the project: one for themselves and the other for their ward/resident in the NH.

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implemented bi-annually in various types of residential care settings including NHs and assisted living facilities.

After mailing introductory letters, site liaisons subsequently called family members and legal guardians to ask if they had received the packet and to address any questions. They also mailed reminder postcards approximately one week later. In addition, introductory family flyers describing the project were placed at strategic locations throughout the NHs, including the reception desk, to create awareness of the project among families and guardians visiting residents.

Staff. Site liaisons distributed introductory flyers to staff and scheduled a date and time with LifeBio, Inc. to conduct the staff training on how to use the life story books to improve person-centered care. Just prior to the training, staff consent forms and baseline (T1) surveys were distributed and collected. BRIA staff hand-delivered many of the T2 surveys to staff, with assistance from some liaisons. For staff members who could not be reached when BRIA staff were on site, T2 surveys were mailed to the address they provided in their T1 survey.

Volunteers. Introductory flyers were distributed at various community agencies by UHCAN Ohio to recruit volunteers. Volunteers were also recruited through personal contacts, emails and via the telephone by UHCAN Ohio and partner organizations. Once recruited, volunteers were trained to collect life story information from NH residents and were informed that their contact information would be released to BRIA for the evaluation. Upon completion of the life story interviews, UHCAN Ohio provided BRIA with the contact information of volunteers who had conducted life story interviews. The volunteers were sent an e-mail with a link to an online post-test survey or a paper copy with a postage-paid, BRIA return envelope.

Training Research BRIA researchers to Gather Data from NH Residents. BRIA recruited and trained 14 research interviewers (referred to as "BRIA researchers" in this document, as distinct from life story interviewers collecting life story information). Most BRIA researchers had a background in long-term care or aging services; they included nurses, nurse aides, social workers, an Ombudsman, and retired teachers. All BRIA researchers were required to take an online course in the protection of human research subjects and submit their certificate of completion to the BRIA Institutional Review Board (IRB) Coordinator.
A training manual (adapted from previous BRIA research projects) was developed to guide an all-day training session. The Principal Investigator from BRIA conducted the training, which included information on in-person interviewing skills with older adults, particularly NH residents, collecting data objectively without bias, obtaining consent, respecting refusals, maintaining confidentiality, tracking number of residents approached (response rates), and role- playing using the resident questionnaire. Initially, new researchers who had not participated in prior BRIA projects or did not have prior expertise in aging were observed by the Project Coordinator while they conducted their initial interview(s) with NH residents. Follow-up trainings were also conducted with all BRIA researchers, focused on their experience after conducting a few interviews with residents.

BRIA worked with site liaisons to schedule research interviews at each site. BRIA researchers then approached residents in person to obtain informed consent, as well as 'assent' from those whose legal guardians had provided consent. The cognitive screen was conducted, and if eligible, the interview with the resident proceeded. Residents with severe cognitive impairment (score of 7 or

below on the BIMS) were thanked for their time but were not asked to complete the rest of the interview.[3]

Institutional Review Board (IRB)

An initial proposal was submitted to The Ohio State University's IRB by GRC on 6/13/2017. After several revisions and modifications requested by the University's IRB, a final determination was received on 2/7/2017 with no IRB review required.

The study's research protocols and materials were subsequently submitted to BRIA's IRB for review on 1/8/2018. The project was approved with minor revisions on 1/19/2018, after which field operations began.

A request for modifications to mail reminder postcards to boost response rates for family members was approved on 3/23/2018. A second modification request was made to change the study design from a wait-list control to pre-post, which was approved on 11/14/2018. All approved consent forms for the project are available upon request.

As of January 21, 2019, when the federal revised Common Rule went into effect, Evaluation of the LifeBio Pilot Study was determined to have met the criteria for exemption from IRB review (Exemption 2). Therefore, in future studies of this nature, it is likely that only limited IRB review will be required to ensure privacy and confidentiality of participants.

HIPAA and Data Protocols

All data for the project were sent and received using HIPAA-compliant methods. All partners signed business associate agreements and data use agreements. BRIA set up a secure transfer file protocol for transmission of identifiable data to and from project partners.

Data Management and Analyses

Data were cleaned and prepared for analysis with SPSS software. Separate datasets were created for each type of study participant. Descriptive statistics were generated for demographic data. Comparisons of individual items with dichotomous or categorical response choices at pre-test and post-test were analyzed with the McNemar test, which is used for paired or dependent samples. Comparisons of items as interval level measures (several response choices, ranging, for example, from strongly agree to strongly disagree), at pre-test and post-test were analyzed with paired-samples t-tests. As mentioned in the measures section, scales combining related items were created where appropriate; for example, depression, satisfaction with the nursing home, and quality of life. Mean scores for these scales at pre-test and post-test were also analyzed with paired-samples t-tests.

[3] Note: After the research evaluation was completed, all residents in a NH were given the opportunity to be interviewed for their life story and receive a book, action plan and summary.

Response Rates of Study Participants

Residents

Sampling information and response rates for residents can be found in Table C1 in Appendix C. Site liaisons identified a total population of 1,817 residents at the 16 participating NHs at the time of initial meetings between BRIA and NH sites. (It should be noted that numbers in Table C2 differ from those in Table C1 because data from Ohio Governor's Office of Health Transformation and the Centers for Medicare & Medicaid Services were obtained at different time periods.) After identifying residents who were Medicaid-eligible, long-stay, age 60 years or older, with a BIMS score of 8 or higher, English-speaking, and not residing in a locked unit or on hospice, 569 residents met the eligibility criteria for the project. Of the 569 eligible residents, 37 legal guardians did not give permission to approach their wards and another 174 residents declined to have their contact information released to the research team, leaving a total of 358 residents who agreed to meet with BRIA researchers.

Once BRIA began data collection, of the 358 NH residents who had agreed to have BRIA researchers approach them, 20 residents failed the BIMS on the day of the interview, and 21 residents were unavailable at the time of interview, leaving a sample of 317 eligible residents. Of these, 79 residents refused to participate. A total of 238 interviews were completed at T1, for a response rate of 75% (refer to Table C3 in Appendix C).

Of the 238 residents participating in T1, 35 residents were unable to be interviewed at T2 (due to being transferred, discharged, or too ill to participate), leaving a sample of 203 eligible residents. Of these eligible residents, 17 refused a life story interview, and 186 residents completed the T2 interview, for a response rate of 92%. Of the 186 residents participating at T2, 14 were unavailable at T3 (also due to being transferred, discharged, or too ill to participate), leaving a sample of 172 eligible residents. Of the latter, two residents refused to participate, resulting in a total of 170 completed T3 interviews, for a response rate of 99% (refer to Table C4 in Appendix C).

Staff

Of the 212 staff members attending the LifeBio staff trainings, 198 staff completed T1 surveys prior to the training for a response rate of 93%. (Note: the staff were a captive audience, as they were surveyed immediately before the staff training.) At T2, BRIA was informed that 16 staff members were no longer employed. Also, an administrator and a site liaison who were not present at the initial training requested a T2 survey, leaving an eligible sample of 182 staff. At T2, 92 (50%) staff completed the surveys (refer to Table C5 in Appendix C).

Family Member and Legal Guardians

Response rates for family members were not calculated at T1, as BRIA did not receive information on the number of survey packets that were mailed by participating NHs to the 'most involved' family members. Likewise, BRIA did not receive information on the number of residents who did not have involved family members. Although the project team received 69 completed family surveys at T1, 13 residents associated with these family members refused to participate at T1, and 10 more residents refused to participate at T2. Thus, 56 family members of participating residents

returned a T1 survey, and 46 follow-up family packets were mailed at T2 to family members of residents who continued to participate. BRIA received 30 T2 family surveys for a response rate of 65%. (Refer to Table C6 in Appendix C).

Volunteers

UHCAN Ohio recruited and trained 31 community volunteers to conduct life story interviews. After delays in the project timeline, many UHCAN Ohio volunteers lost interest or were unavailable during the winter months when the project re-started. Ultimately, 14 community volunteers participated in conducting life story interviews in seven of the 16 NHs participating in the project. These volunteers conducted 30 life story interviews, which was about 16% of the total of 186 NH resident life story interviews that were completed. Of the 14 volunteers who completed or assisted with life story interviews, 11 completed the T2 survey (post-test only methodology) for a response rate of 79%.

Timeline for the Project

Although study procedures were designed with formal guidelines and strict timeframes, it is important to note that there were considerable time lags in gathering the T1, T2 and T3 resident data because of administrative delays after each fiscal year ended. The median number of days between T1 and T2 resident interviews was 99 (range 2 to 370 days). The median number of days between T2 and T3 resident interviews was 72 (range 38 to 311 days). The median number of days between T1 and T3 resident interviews was 286 (range 84 to 416 days).

Findings

NH Sites

The 16 NHs participating in the project served a total of 1,939 residents, with an average of 121 residents per NH (range, 61 to 165; Centers for Medicare & Medicaid Nursing Home Compare, FY 2017). Of the total number of residents, 1,413 (73%) were Medicaid-eligible (Ohio Governor's Office of Health Transformation, 2017).

Four of the 16 NH sites were in Ashtabula County, i.e., a rural area of Ohio, while the remaining 12 were in Cuyahoga County, which is a mix of urban and suburban areas. Of these, 13 (81%) were proprietary sites and the other three were non-profit NHs. This is fairly representative since the majority of NHs (approximately 79%) in Cuyahoga and Ashtabula Counties are proprietary. Their Nursing Home Compare overall quality star ratings ranged from 1 to 5, consistent with the sampling goals for recruiting a wide range of NHs with differing characteristics. See Table C2 in Appendix C.

Residents

Background characteristics from the MDS. Background characteristics of some participating residents were obtained from MDS data (except for gender, which was obtained from residents' life story interviews. Two-thirds of the sample was female). The most recent MDS data provided to BRIA was from June 30, 2018 and contained information on 174 (73%) of the 238 nursing home

residents who participated in a baseline interview at T1. The median age of residents at T1 was 79 years (range, 54 to 102 years), and four residents were younger than the study eligibility criterion of age 60. In terms of marital status, 38% were widowed and 25% were divorced or separated, 21% were never married, and 15% were married.

Residents' median length of stay from admission to their baseline T1 interview was slightly under 3 years (range, less than a year to approx. 34 years). An examination of the Patient Health Questionnaire (PHQ-9) scoring found that more than two-thirds of the residents had no depressive symptoms, while 15% each had minimal depressive symptoms or minor depression; only two residents were scored as having moderately severe major depression. On the other hand, 61% of the residents were found to have received an antidepressant medication in the last 7 days, either alone (10%) or in combination with an antipsychotic, antianxiety and/or hypnotic medication, while 29% did not receive any of these medications. No physical restraints were used with any of the participating residents.

Background characteristics from BRIA surveys. Demographic characteristics of the 238 residents in our sample, based on their T1 research interviews, are shown in Table 1.

Cognitive status. The BIMS was used to assess residents' cognitive status at T1 and at T3. Scores for eligible participants ranged from 8-15, and averaged 13 at T1. Scores of 13-15 for 65% of the respondents, who are thus characterized as cognitively intact, while 35% scored between an 8 and 12, indicating moderate cognitive impairment. At T3, residents were re-tested, and of the 170 completing interviews, approximately 60% scored as cognitively intact, 35% scored as moderately impaired, and 5% scored between 2 and 7, indicating severe impairment. Nevertheless, interviews were continued with all residents based on the resident's willingness to continue, as well as the BRIA researchers' judgment and experience working with older adults.

A paired t-test was conducted to determine if the mean levels of cognitive impairment differed from T1 to T3, and the results indicated that there was a significant decline in mean BIMS scores from T1 (M = 13.08, SD = 2.20) to T3 (M = 12.53, SD = 2.81), $t(168) = 2.881$, $p = 0.004$.

Table 1
Resident Demographics and Characteristics from T1 Surveys (n=238)

Characteristics		
Age (mean years)		77 (Range: 54–101)
Gender		
Female		66%
Highest Level of Education		
Less than High School Diploma		26%
High School Diploma		36%
Some College		19%
Associate's Degree		6%
Bachelor's Degree		9%
Master's Degree or Other Post-Graduate Degree		5%

Length of Stay		
Less than One Year		23%
One to Five Years		52%
More than Five Years		25%
Has children, relatives or friends who contact by visiting or calling		
Yes		87%

Activities of Daily Living (ADL). In terms of assistance, at both T1 (n = 283) and T3 (n = 170), residents often needed some help or complete assistance with walking (84% and 82%, respectively), bathing (79% and 71%, respectively), dressing and undressing (54% and 48%, respectively), getting in and out of bed (48% and 46%, respectively), taking care of their appearance (35% and 36%, respectively), and eating (15% and 13%, respectively).

A paired t-test was conducted of the ADL scale created from these items to determine if significant changes in levels of functional impairment occurred between T1 and T3. Results indicated that the average decline in ADL approached significance from T1 to T3.
(M = 9.74, SD = 2.64) to T3 (M = 9.50, SD = 2.59), $t(167) = 1.638$, $p = 0.103$).

Satisfaction with Care in the NH. Findings revealed no significant differences between T1 and T3 in the proportion of residents reporting satisfaction with any of the 8 individual items. Further, in terms of the Satisfaction with Care scale, relatively high levels of satisfaction were reported during both time periods, and no significant difference was found by a paired t-test between the mean scores at T1 and T3.

Perceived usefulness of life stories. Overall, the majority of residents agreed with these statements. Roughly 64% of residents at T1 (n = 238) responded that it was important for staff to know their stories, and approximately 60% thought staff were interested in learning their stories. Of residents participating at T3 (n = 170), 73% agreed it was important for staff to know their life story, and 63% agreed that staff were interested in learning their life stories. No significant difference was found by a paired t-test of the mean scores at T1 and T3 for either of these items.

Life story interview experience and intention to share life stories. As mentioned earlier, the items on the experience of participating in the life story interviews were measured only at T2 and T3. At the conclusion of the life story interview, 186 residents answered questions at T2 (see Table 2 below). The experience questions were re-assessed with 170 residents at T3, roughly 30 days after the delivery of residents' life story books. McNemar tests were conducted on individual items from T2 to T3 for these experience questions and differences in the proportion of residents reporting positive responses to some of these questions were identified. This analysis was limited to those who answered these questions at both the T2 and T3 interviews (refer to Table 2).

Table 2
Differences in Resident Life Story Interview Experiences Between T2 and T3

	T2	T3

Question	*n*	%	%	McNemar *(p)*
"Did you enjoy telling your life story?"	157	95%	86%	0.019*
"Did you have enough time with the interviewer to share your life story?	154	88%	83%	0.281
"When you get your life story book, will/did you share it with family and friends?"	150	95%	62%	0.000***
"When you get your life story book, will/did you share it with the staff that care for you?"	150	90%	44%	0.000***
"Do you think the nursing home staff will provide/are providing better care to you after they know your life story?"	125	62%	41%	0.000***
"Do you think it is important that your life story book is being created?"	136	95%	82%	0.000***
"Would you recommend the life story program to other nursing home residents?"	148	93%	87%	0.167

* $p < .05$, *** $p < .001$

Physical health. Overall, the majority of residents reported being in good health at both time periods, with roughly two-thirds of residents' reporting themselves as being in "good" to "excellent" health at T1 (n = 238), and approximately 70% reporting as being in "good" to "excellent" health at T3 (n = 170). A paired t-test was used to examine the difference in mean self-reported physical health between T1 and T3; there was no significant change.

Mental health. Approximately 76% of residents reported their mental health was "good" to "excellent" at T1 (n = 238), and roughly 81% reported "good" to "excellent" mental health at T3 (n = 170). A paired t-test was used to examine the difference in mean self-reported mental health between T1 and T3; there was no significant change.

Depression. With respect to depressive symptomatology based on the Patient Health Questionnaire scale, more than half (53%) of residents at T1 (n = 238) experienced some mild to severe symptoms of depression, with 32% experiencing mild symptoms, 19% experiencing moderate to severe symptoms, and 2% indicating severe depression. At T3 (n = 170), the number of residents reporting mild to severe symptoms of depression dropped to roughly 41%, with 24% reporting mild symptoms, 13% reporting moderate to severe symptoms, and 4% reporting severe symptoms.

A paired t-test was conducted to determine if there was a significant change in mean levels of depressive symptomatology between the residents' T1 and T3 interviews. A significant decrease was found in depressive symptoms over time between T1 (M = 5.59, SD = 5.10) and T3 (M = 4.71, SD = 5.46); $t(168) = 2.46$, $p = 0.015$.

Quality of Life – Global and OPQOL. Overall, residents reported a positive global quality of life; thus, treatment effects were difficult to identify. At T1 (n = 238), approximately 95% of residents rated their quality of life as "all right" (32%), "good" (35%), or "very good" (28%). At T3 (n = 170), roughly 92% of residents rated their quality of life as "all right" or above, with 22% reporting

“all right,” 35% reporting “good,” and 34% reporting “very good.” A paired t-test was conducted to examine differences in mean levels of quality of life between time periods, and no significant difference was reported between T1and T3.

With respect to the OPQOL scale, roughly 75% of residents at T1 (n = 238) reported they agreed or strongly agreed that they enjoy their life overall, 89% that their friends or family would help them if needed, roughly 60% that they could do as they please in the NH, and 87% that they take life as it comes and make the best of things. At T3 (n = 170), roughly 83% of residents agreed or strongly agreed that they enjoy their life overall, 88% that their friends or family would help them if they needed it, 66% that they could do as they please in the NH, and 88% that they take life as it comes and make the best of things. No significant difference was found from T1 to T3 for these items.

Resident Comments: Comments provided by residents expressed a fairly diverse range of opinions. About 25% of all resident who provided comments at T2 made statements related to the *positive nature* of the care that they received:

- “Of the three places I've spent a significant amount of time, this [NH] was the best.”

- “Satisfied, eat well, sleep well, go her own way and do what they want me to. Don't bother me and I don't bother them.”

- “The care is alright and the facility is alright. I think they helped me accomplish what I needed to do, set health back on track and made sure I got my appointments and took my medicine."

- [Regarding the life story program] I liked it because it was personal. We talked about what I like to do. I liked singing with the interviewer.”

Some of the *comments indicated mixed feelings* and included:

- “Like I said, care had really gone downhill over the past few years, early on…we were cared for very well when I first got here. I can speak for myself where things aren't going right. Sometimes I wonder what happens to those who can't. With every job you have people who are there for a pay check and some are here because they love this work. I say to a lot of these young girls how to much it would mean to someone to stick your head in their door and say hello. It would mean the world to them. Like I said, some people are here because they love the work, others just because it's all they can do.”

- “Only thing is, I think they need to hire more help. Staff tends to pitch stuff in the corner. I don't have anybody to empty my bags out. I keep things close so I don't have to ring the buzzer every 5 minutes cause I know they ain't got time. They ain't got the help. I go with the flow. I don't see my daughter that often, too far out from the bus line. These are nice places, I don't put them down, for people with no places to go they are Godsends but I been here too long.”

Some residents (21 total) made reference to errors or inaccurate information in their life story book. LifeBio implemented procedures to receive information about errors and correct mistakes. .

- "[Resident stated the] information [was] not entered in correctly - would like corrections made. Would like new corrected copy before she shares it with others."

- [Regarding the LifeBio program]. "There were a few errors in the booklet. Did not share with staff or post. I am a very private person. Everyone from LifeBio has been [very] respectful [and] nice to me. Found the booklet [very] helpful/communication tool with my family."

- "Disappointed in the level at which the information is communicated - felt it was like a 5th Grade level - 'offensive' - so much so did not want to place it on the wall or share with family. Incorrect grammar [and] information, would have been great to see a draft. Felt information was not all captured."

Staff

Background characteristics. There were 198 staff surveys received at T1, an average of approximately 12 for each of the 16 participating nursing homes (range, 1 to 37). Slightly fewer than half (46%) of the staff who completed a T1 survey also completed a T2 survey, with an average of approximately 6 completed staff surveys in each nursing home (range, 1 to 15). (See Table C5.) Their median length of employment in NHs was 12 years (range, 0 to 45) and their median tenure in the NH where they worked at the time of the study was 5 years (range, 0 to 35). (Refer to Table 3 below).

Table 3
Staff Demographics and Characteristics from Time One Surveys (N=198)

Characteristics		
Age (mean years)		44 (Range: 17-76)
Gender		
Female		93%
Race		
White		70%
African American		24%
Hispanic		4%
Asian		2%
Other		1%
Highest Level of Education		
Less than High School		3%
High School Diploma		28%
Some College, No Degree		25%
Associate's Degree		20%

Bachelor's Degree		16%
Master's Degree or Other Post-Graduate		
Job Title		
Licensed Nurse		24%
Nurse Aide / Assistant		23%
Activities Staff		20%
Social Worker		8%
Administrator		7%
Physical/Occupational/Other Therapist		6%
Support Staff		5%
Admissions Staff		3%
Office Staff		2%
Other Administration		1%
Full-time employee		91%

Job satisfaction. Examination of the impact of the LifeBio program on nursing home staff members' job satisfaction was limited to staff who completed those 10 items on both the T1 and T2 surveys. A statistically significant change (increase) was found for only one item: "How satisfied are you with the way management and staff work together?" [$t(78) = -2.699$, $p = .009$]. See Table 4 below.

Table 4
Comparison of T1 and T2 Staff Responses to Job Satisfaction Questions

How satisfied are you with...	Mean Difference Between T2-T1	Standard Deviation	*t*	df	Significance
The working conditions here?	-0.049	0.683	-0.647	81	0.520
The recognition you get for your work?	0.099	0.768	1.157	80	0.251
The attention paid to the suggestions you make?	-0.012	0.750	-0.148	80	0.883
Your pay?	-0.063	0.757	-0.743	78	0.460
Your fringe benefits?	-0.050	0.778	-0.575	79	0.567
The amount of time you have to get your job done?	-0.087	0.845	-0.926	79	0.357
The teamwork between staff to improve care provided to residents?	-0.125	0.769	-1.453	79	0.150
The way management and staff work together?	-0.228	0.750	-2.699	78	0.009**
The way you are included in resident care plan meetings?	-0.014	0.736	-0.159	72	0.874
If a friend or family member was thinking about taking a job at the nursing home where you work, and asked your advice, would you recommend it?	T1 Yes = 86% T2 Yes = 83%			n = 72	(McNemar Test) 0.754

Note. The range of responses for the first 9 items above is 1 = Very dissatisfied to 4 = Very satisfied. The last item is a yes/no question and was analyzed with a McNemar rather than a *t*-test.
**$p < .01$.

Perceived usefulness of life histories. Similarly, examination of the staff members' perception of the usefulness of creating residents' personal life stories was limited to staff who completed those three items on both the T1 and T2 surveys. Response choices for these items ranged from 1 = Strongly Disagree to 5 = Strongly Agree. Again, a statistically significant change (increase) was found for only one item: "It is important to me to know about the residents' life stories." [$t(89) = -2.160$, $p = 0.033$]. See Table 5 below.

Table 5
Comparison of T1 and T2 Staff Responses to Questions About Perceived Usefulness of Residents' Life Stories

	Mean Difference Between T2-T1	Standard Deviation	*t*	df	Significance
It is important for me to know about the residents' life stories.	-0.122	0.537	-2.160	89	0.033*
I am <u>not</u> interested in learning about the residents' life stories.	-0.060	0.896	-0.609	83	0.544
I would provide better care to the residents knowing their life stories.	-0.103	1.285	-0.751	86	0.455

Note. The range of responses for the first and third items above is 1 = Strongly disagree to 5 = Strongly agree. The second item was reverse coded.
*$p < .05$.

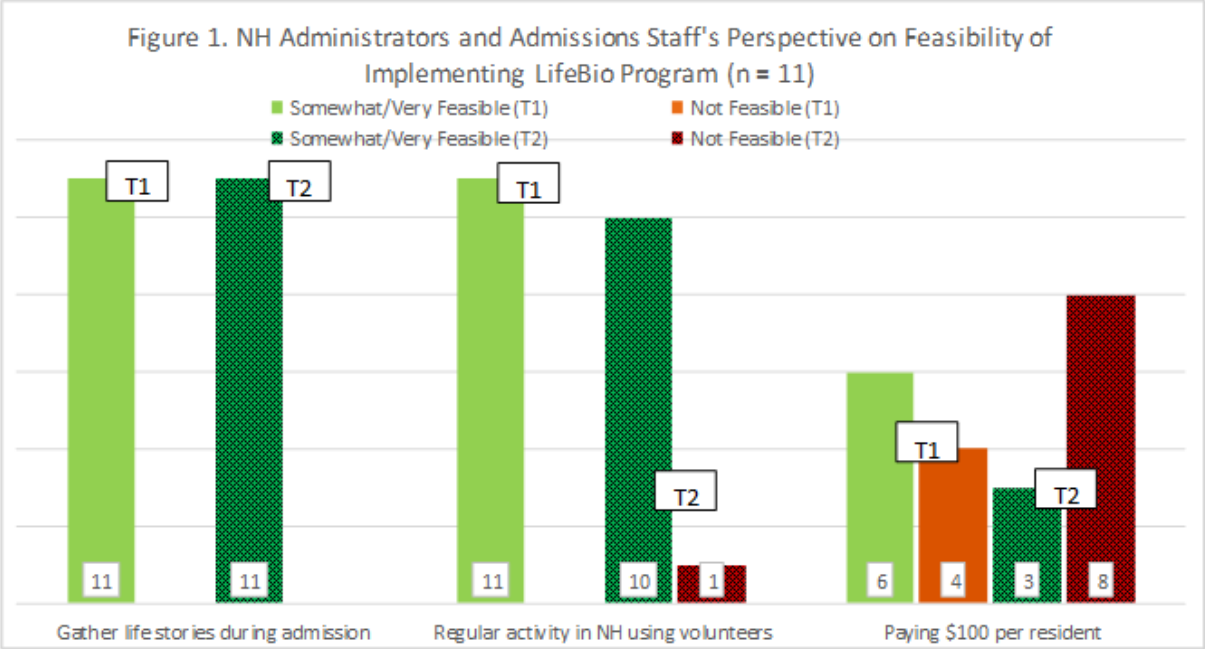
Staff Experience with the LifeBio Program at T2. In terms of the LifeBio program, staff had very positive experiences with the LifeBio program. See Table 6 for details.

Table 6
Staff Experiences with the LifeBio Program and Materials at T2

Question	*n*	Agreed or Strongly Agreed
"I used the information from the residents' life stories in their care plans."	87	76%
"I enjoyed learning the life stories of residents."	90	95%
"It's important that the residents' life stories were created."	87	100%
"The quality of the life story booklets were excellent."	91	92%
"The quality of the one page life story summaries were excellent."	89	94%
"The one page life story summaries were very useful in my work."	89	85%

"I have enough time to use the information from the one page summary of residents' life stories when talking to residents"	89	85%
"I would recommend the resident life story program to other nursing homes."	89	86%

Feasibility. Nursing home administrators and admissions staff were asked to complete supplemental questions regarding the feasibility of collecting data on a resident's life history during the admissions or intake process. One representative each from 11 of the 16 participating NHs responded to the questions; 8 were administrators and 3 were admissions staff. All 11 agreed at T1 and at T2 that it was somewhat or very feasible to do so. They were also asked about the feasibility of gathering residents' life histories as a regular activity or program offered to residents in their NH if volunteers were provided for the activity. At T1, all 11 responded that this would be somewhat or very feasible, although at T2, one individual changed the response to "not feasible." The final question asked about the feasibility of gathering residents' life histories as a regular activity or program offered to residents in their NH if volunteers were provided to do so and if the NH also had to pay about $100 per resident. Of the 10 individuals who answered this question at T1, 6 responded that it would be somewhat or very feasible; at T2, only 3 of the 11 individuals answered this question positively (refer to Figure 1).



Staff Comments: Some of *the positive comments* included:

- "I truly believe the concept of your [LifeBio} program would make a huge difference in how staff care for our residents. We would be more educated of their history and what they enjoyed, loved, believed, etc. With such knowledge you can provide better care through conversation,

creating a better bond with them and you would know more to better take care of them when their dementia increases/progresses and they can't tell you those things anymore."

- "The LifeBio project is greatly appreciated. Many times residents are known by their medical condition rather than who they are as a person. This LifeBio project has been a great success to our residents & staff. It helps to enhance the memories of each resident & gives an opportunity to take pride in their accomplishments. This is also a learning experience for our staff to see our residents as individuals--grandmother, mother, sister, etc."

Other staff commented on *some of the challenges* faced in the project:

- "We were not given the opportunity to pass out all of the life stories back to residents. I was never given enough time, even to take all my breaks daily to work it in. Once they [life story books] sat there for over a month, they were distributed by just handing the whole thing to the remaining residents. Whereas the several that I did get time to pass out, I was able to sit and read both the book and the fact sheet to the resident. Just saying."

Family

Background characteristics. Of the 56 family members participating in T1 surveys, ages ranged from 33 to 90 years, with a mean of 64. The sample of family members was comprised mostly of females (71%). Family members had a wide variation in educational attainment, with 20% completing some form of post-graduate degree, 20% completing a bachelor's degree, 32% completing an associate's or some college, 26% with a high school diploma, and 2% with less than a high school diploma. In terms of racial composition, the sample was primarily White (82%), followed by Black or African American (16%), and then Hispanic or Latino (2%). They had a variety of relationships with residents; the children of residents comprised a plurality (45%), followed by siblings (20%) and spouses (13%), and a variety of other relatives and friends. Many of the most involved family members reported that they visited their relative frequently, daily or several times a week (52%) or once a week (26%); others visited less often.

Satisfaction with resident care in the NH. At both T1 and T2, family members were likely to rate satisfaction with their resident's care positively, thus, the ability to observe significant improvement following LifeBio was limited. At T1 (n = 56), 91% of family responded "probably, yes" or "definitely, yes" to residents having opportunities to engage in meaningful activities versus 82% at T2 (n = 30). Roughly 94% of family members at T1 responded that residents' preferences were probably or definitely being carried out, versus 83% of family members who responded at T2. Approximately 93% of family members at T1 also responded that NH staff probably or definitely knew what the resident liked and disliked, compared to 97% at T2. The majority of family (85%) at T1 also said staff definitely or probably went above and beyond to give residents a good life versus 82% at T2. Finally, 94% responded at T1 said that they would probably or definitely recommend the nursing home to a family member or friend, versus 89% at T2. Paired t-tests were conducted on individual items and the scale combining all of the items; however, no significant differences were found between T1 and T2.

Perceived usefulness of life stories. At T1 (n = 56), roughly 75% of family members agreed or strongly agreed that it was important that staff know their relative's life story compared to 70% at T2 (n = 30). At T1, 52% agreed or strongly agreed that staff were interested in learning their resident's life story compared to 57% at T2. Finally, 51% of family members agreed or strongly agreed at T1 that staff knowing a resident's life story could help them provide better care versus 47% at T2.

A paired t-test was then conducted to test for a significant difference in mean scale scores over time. The results indicated a significant decrease from T1 (M=3.63, SD = 0.928) to T2 (M = 3.23, SD = 0.858); $t(29) = 2.112$, $p = 0.043$).

Family comments. Some of the *positive comments* included participating in the LifeBio program included:

- "I saw my sister's bio on the wall in her room. She is very proud and happy to talk about her life prior to being in a nursing home. This was a great undertaking for her and the residents in general. Thank you very much!"
- "My father enjoyed telling his life story and then seeing it 'published'. My father left the world on February 28, 2019. We, my family, are grateful he had the opportunity to participate and displayed it in his honor at his wake."
- "What a wonderful way for her [relative in NH] to leave us and future generations her life story. Thank you."

Other comments that reflect *mixed feelings* regarding the LifeBio program included:

- "If my mother agrees to talk with you, then do so. My signature and my life (race, education) and age) have nothing to do with her bio. I am a very private person and take good care of my mother and me & my siblings make sure others do the same."
- "During the interview I was asked for pictures. Who do I provide/send the pictures to and where should they be sent? What is the purpose of this survey [and] will I be informed of the results? Knowing the questions in advance would assist in trying to find the answers from other family members."

Positive comments regarding NH care included:

- "My mother and father were both living at [name of nursing home] until my mom passed away in 2014. They both received such good care at [name of nursing home] and the staff is excellent."
- "Since I visit my brother 1-2 times per year, I cannot give firm answers to any of these questions. I can only provide 'general' responses based upon the types of situations my brother tells me about and complains to me. When I do visit, the staff are very friendly and willing to discuss [participant name]. We do conduct 1/3 month care conference calls to discuss his

attitude health and care. These conferences leave me with the impression that he is pretty well cared for and that his needs are being considered."

Mixed feelings regarding care in the NH included:

- "In my experience with this and other nursing facilities that staffing (especially holidays and weekends) are a large impediment to excellent resident care. Also, staff need to be trained to be more patient with the geriatrics. The residents should be approached as adults with choices…"
- "I believe that the facility is usually very short staffed. When this happens (and it's frequently) the remaining staff does not have the opportunity to listen or learn from [participant's name]."
- "Seems that there is a lot of turnover in the aides that work there which can be an issue. New aides need trained and don't know what my mom's needs are…"

Volunteers

Background characteristics. Of the 11 volunteers completing the post-survey, all but one was female, all had at least some college experience, and their average age was 70 years (range, 62-82). All but two of the 11 volunteers identified their race as White. Previous volunteer experience was reported by eight volunteers, and they had volunteered for median of eight years (range 1 to 44). However, only four volunteers reported that they had previously volunteered at a nursing home.

Experience with the LifeBio project. Overall, the experience of the 11 community volunteers was very positive. At least 10 of the 11 responded positively (agree or strongly agree) to questions about the importance of knowing residents' life stories at the NHs where they volunteered, and interest in learning about residents' life stories. Nine of them responded that knowing resident life stories would make them better volunteers. Similarly, all the volunteers gave positive (agree or strongly agree) responses to questions about enjoying hearing residents' life stories and recommending the life story program to other volunteers. All but one agreed or strongly agreed that they had enough time to gather the residents' life stories. The usefulness of the life stories to care staff and the training provided were also viewed positively by 9 of the 11 volunteers. The lowest percentages of positive (satisfied or very satisfied) responses were given to questions about interactions with nursing home staff (7 of 11), supplies provided (7 of 11), and the nursing home environment (8 of 11). With respect to volunteers collecting resident life stories in NHs across the state, all but one agreed or strongly agreed that this was feasible.

The most frequent reason endorsed for volunteering in the LifeBio project was the opportunity to learn about other people's histories and backgrounds, followed by enjoying volunteering with older adults.

Volunteer Comments: Comments provided by this small number of volunteers expressed a fairly diverse range of opinions. Some of *the positive comments* included:

- "I would love to do this again, if they expand it further in this state."

- "[Name of staff at UHCAN Ohio] was terrific & well organized to assist us. It is a fine program that enriched my life. I would do it again in a heartbeat."

Some of the *comments indicated mixed feelings* and included:

- "I enjoyed doing this, yet because of project scheduling change, I didn't get to do many."

- "I think this project is a great idea. However, I went on my lunch hour with limited time to spend. I met with two residents who decided, after I spent some time with them, that they did not want to participate. Better screening, if possible, would have helped. When I met with my third resident, she got bored midway through and asked how long the questions would continue, so I did not complete all the questions."

In addition, volunteers made some suggestions:

- "The more information you have about a person, and interacting with those people, gives them a feeling of comfort when they can talk about themselves. All of the information we gathered could probably be in a social service note or file."

- "I wish this survey was done immediately after the experience. It's been over a year and it's difficult to remember some of the details. I do recall the staff was not informed about what to do. I don't feel I can do something like this outside of my area where I would have to drive...I happened to get two wonderful ladies that I keep up with now whenever I'm in the area..."

For more information on the volunteer experience with the LifeBio program, refer to the report by UHCAN Ohio in Appendix D.

Additional observations by LifeBio, Inc. and UHCAN Ohio regarding the program implementation and feedback from residents, staff, family, and volunteers is available in Appendices D and E.

Section II. Opening up the Life Story Project to All NH Residents: Conducted by LifeBio, Inc.

Methods

After the completion of the research interviews at each site, a second wave of the life story program was offered to all residents in the participating NHs who did not meet the study eligibility criteria. Utilizing a simple post-test methodology, residents participated in a life story interview, and answered a short demographic survey along with seven questions about their experience. Residents were recruited directly by nursing home staff using flyers and sign-up sheets provided by LifeBio, Inc. About half of these life story interviews were conducted with the involvement of a NH staff member at one NH, and the rest were conducted over the phone by LifeBio, Inc. staff. Resident surveys were then sent by LifeBio, Inc. via FTP for data entry by GRC, which sent the data on to BRIA for analysis.

Resident eligibility. For this section of the study, eligibility requirements were dropped entirely and any resident in a participating NH who wished to participate could do so, regardless of BIMS score, payer type, length of stay, or age.

Findings

Resident characteristics. There were 12 residents from three NHs who participated in the supplemental arm of the project after the evaluation had been completed. Their ages ranged from 33 to 96 years, with a median age of 80; 7 of the residents were male. The racial composition of the sample was white, except for one participant who identified as "other" without specifying their race. The participants' highest level of education was some college but no degree (5); the rest except for one had a high school diploma. The majority of residents (7) had been in the NH for 1 to 5 years, followed by less than one year (3); only one resident had been in the NH for more than 5 years.

Experience with life story interviews. Residents involved in the supplemental portion of the project were asked seven questions related to their experience and perceptions of the life story program, similar to the T2 questions asked of residents participating in the research study. Much of their experience was very positive, with all the participating residents stating that they enjoyed telling their life story and intended to share their life story book with family and friends. In addition, all but one resident responded that they had enough time with the interviewer to share their life story and that they intended to share their life story book with staff members who cared for them.

When asked if staff would provide better care if they knew the resident's life story, only five responded that they thought they would, five stated they didn't know, and two said they would not. Comments on this question included that they felt care would remain the same; one participant added that "…staff already does a good job caring for me." When asked if residents thought it was important that their life story was being created, all responded positively and also stated they would recommend this program to other NH residents.

Section III. Discussion

Summary of Findings

Resident experiences. In examining the experiences of residents participating in the interviews to collect their life stories, results indicated that they enjoyed participating in the LifeBio program; anecdotal evidence of these positive experiences can also be found in LifeBio, Inc.'s Observations and Feedback report in Appendix E. More than 80% of residents reported positive experiences with the program at both T2 and T3: they enjoyed telling their life story, had enough time with the interviewer to do so, thought it was important their life story book was created, and would recommend the program to other residents.

However, a significant decrease was observed over time in resident responses concerning whether staff would provide better care to them as a result of knowing the resident's life story. Regarding the importance of staff knowing resident life stories or being interested in such information, the majority of residents indicated that they intended to share their life stories with staff and many had done within the first month. Resident perceptions about the quality of their care did not change over time. Anecdotally, research interviewers found that residents were generally content with the care they received; some understood staff constraints and so indicated that they didn't believe care would change due to sharing their life story books. Some residents expressed concern about incorrect information in their life story booklets that required correction prior to sharing. These

process-level findings suggest that residents' willingness and ability to share their books is an important component of successful life story work.

No significant differences were found between T1 and T3 regarding residents' satisfaction with NH care. Residents were already reporting high levels of satisfaction with the care they were receiving, as has been found in Ohio's NH resident satisfaction in general, except in areas related to meals and laundry where there was more variation (Wheatley et al., 2007). The lack of variation made it difficult to detect changes or improvements in resident satisfaction with care.

In terms of research questions for residents, significant changes in depressive symptomatology as measured by the PHQ could provide some evidence that LifeBio participation was beneficial. This is consistent with findings from prior studies reporting that residents engaging in life story work reported lower scores on measures of depression (Morgan & Woods, 2010); however, it also conflicts with evidence from a recent randomized controlled trial that found no significant decrease in depression (Subramaniam, Woods, & Whitaker, 2014). This may be the most significant finding from our pilot project, and could support the wider roll-out of the program to test its generalizability in other NHs across the state.

With respect to self-reported physical health and mental health, there was a lack of significant change between T1 and T3 to provide evidence that the LifeBio program had a measurable impact on these outcomes. Residents' ratings of happiness, global quality of life, and quality of life, as measured by the OPQOL, were very high at both T1 and T3, making it difficult to identify whether the LifeBio program impacted these outcomes in this pilot project. Although another study reported improvements in QOL after application of a life story book-based intervention (Subramaniam et al., 2014), its methods included 12 weekly sessions conducted by a clinical psychologist. This difference in delivery of the intervention, combined with the limited sharing of the life story booklets and the extended timelines between data collection points in our pilot project, may have also influenced the results.

Staff experiences. In terms of staff outcomes, one measure related to staff job satisfaction, staff perceptions of management and staff working together, showed a significant improvement over time. This could be related to increased collaboration between staff and management during this project. Another significant increase was related to staff's endorsement of the importance of knowing residents' life stories. Although, this does not align with resident perceptions, the positive experiences of staff support findings from other studies about life story work: it can assist staff in understanding residents' interests to provide personalized care (Berendonk & Caine, 2019), in positively changing their perceptions of residents (Eritz et al., 2016), and in developing a sense of opportunity to connect through life story information (Kellet et al., 2010). Responses to the LifeBio program experience questions in post-life story interviews also indicated that the majority of staff agreed that the creation of life story booklets was an important endeavor, the materials were of excellent quality, and they were useful in their work. Anecdotal evidence mentioned in LifeBio, Inc.'s Observations and Feedback in Appendix E from staff and site liaisons suggests that staff found information in the life story books useful, some NHs incorporated books into their "standup" meetings, and other staff reported learning new information about a resident they had not known before.

Family experiences. There is limited evidence from the family surveys to support examination of our research questions due to low participation. Because satisfaction with NH care was high initially, and no significant change occurred over time, it is difficult to gauge whether the LifeBio

program had a measurable impact on family satisfaction with resident care. Other studies of family members of NH residents have also found very high levels of satisfaction with care except for areas such as food, activities, the way complaints are handled, and cost (Ejaz, Noelker, Schur, Whitlatch, & Looman, 2002), and laundry, admissions process, and choice (Ejaz, Straker, Fox, & Swami, 2003).

In terms of the perceived usefulness of life stories, a significant decrease over time was noted among family members. This could be due to waning interest in the program because of unexpectedly long intervals between the baseline and post-program surveys of family members. Residents were also initially excited to share these books with their families. It is possible that family members' busy schedules and circumstances (Lam et al., 2018) impacted the results. In addition, other studies have found that engaging in life story work with a relative in a nursing home can be a difficult, emotional experience for a family caregiver, although it may assist family in seeing residents in a more holistic way after the fact (Kellett, Moyle, McAllister, King, & Gallagher, 2010).

Volunteer experiences. Although only 14 volunteers gathered life story information from NH residents in this pilot study, their overall experience was very positive, and they found it enjoyable. However, once again, administrative delays in collecting the information may have caused some volunteers lose interest in the program. More information on this can be found in the report from UHCAN Ohio in Appendix D.

Limitations and Challenges

This pilot project encountered several notable challenges and limitations that are common in studies conducted in long-term care environments, and the project teams made several modifications and adjustments to protocols in attempts to overcome them. Resident factors such as difficulties in recruitment, extremely low cognitive scores, retention, and attrition are known to pose challenges for researchers (Provencher, Mortenson, Tanguay-Garneau, Bélanger, & Dagenais, 2014), as well as staff- and site-level factors, including administrative or managerial turnover (Garcia, Kelley, & Dyck, 2013), and administrative and budgetary constraints influencing timelines of projects (Lam et al., 2018).

Resident recruitment. As seen in Table C1 of Appendix C, significant challenges were experienced during resident recruitment. Initially, stringent eligibility criteria for the study excluded many NH residents, and many others opted out of having their names released to project staff, surprising many staff liaisons/administrators and LifeBio Inc., staff who had implemented the program in other non-NH settings. The evaluation project coordinator informally interviewed nursing home staff and site liaisons to gather feedback regarding residents' reasons for not wanting to participate. Given the highly personal nature of this intervention, common themes suggested that residents were not interested in the intervention, wanted their life story information to remain private, had concerns regarding confidentiality and distribution of life story information, did not wish to re-examine past experiences of hardship or trauma, were embarrassed about their 'bad lives', generally preferred not to engage in any activities, or feared repercussions because they were Medicaid beneficiaries. These reasons for refusals are similar to those commonly found in NH research, including dislike of disruption of personal routines (Hall, Longhurst, & Higginson, 2009), concerns about privacy or confidentiality (Williams, 1993), health conditions, and cognitive impairment (Hubbard, Downs, & Tester, 2003). In response, researchers modified study protocols to allow residents more time to consider participation. The research team also set up further

meetings to discuss barriers to participation and ways to address these. However, since residents have a right to decline participation in any activity, the program was still offered to only those who allowed their names to be released to the project team.

NH and staff participation. In terms of staff and NH participation, of the 16 sites participating, seven experienced managerial and administrative turnover during the project period, exacerbating common problems in long-term care research such as communication with liaisons already busy with competing responsibilities, and scheduling of training sessions and research activities (Mentes & Tripp-Reimer, 2002). Staff members also expressed concerns about the confidentiality of responses to job satisfaction questions, which may have influenced their response rates. However, strong relationships with staff and administrators built by regular face-to-face meetings and incentives such as CEUs for staff helped sustain interest in the project. (We are uncertain whether NH stipends helped maintain interest since this varied greatly among sites; for example, some wanted to use the funds to buy Thanksgiving turkeys for their staff while others forgot that they were getting a stipend.) Further, NHs with a lot of buy-in from senior management and site liaisons helped keep sites engaged and minimized disruption and attrition of sites after baseline interviews were completed. Researchers in turn, had to be flexible so that the demands of participating in a research study did not overwhelm residents or staff participating in the project. In some cases, further delays were caused by factors that required staff to stop project work temporarily; these included outbreaks of scabies (several weeks of quarantine), influenza, or *c.diff*; unannounced state inspections; short staffing, and holidays.

Volunteers. Delays in the project prior to field operations and mid-project disrupted the recruitment and retention of volunteers significantly. Because there were a limited number of volunteers already affiliated with the participating NHs, the project had to rely on external volunteers or LifeBio staff to help fill the gap created by community volunteers who lost interest in the project. The volunteer coordinator initially established relationships with local colleges, community organizations, and religious groups to develop a pool of recruits. The recruitment of volunteers also faced some logistical challenges, for example, transportation for those with limited desire to leave their local area to participate, schedules that conflicted with the availability of NH residents, or the lack of availability of volunteers when the project re-started around Thanksgiving, winter break and the holiday season. Nevertheless, feedback from post-program volunteer surveys indicated an overall positive experience, adequate training, and some willingness to be more involved in future interviews.

Feasibility and Sustainability

For residents, our study indicated the experience of the interview, and the life story book delivery and distribution were high points. Encouraging the sharing of materials makes it easier for residents, staff, and family to continue the life story work process and build on the strengths of the program. Ensuring volunteers, interns, and staff are properly trained and prepared to collect life story interviews with culturally and socioeconomically diverse populations, including those dealing with mental or physical challenges, is critical for the program's success. Modifications to LifeBio, Inc.'s online platform and a robust library of supporting documents will also assist in maintaining continued engagement of residents, family, and staff members by allowing them to collaborate on the story, make revisions to their books (especially factual information about their life), correct grammatical errors, and add photographs to make the books more visually appealing.

A very important aspect of feasibility overall in this project relates to its implementation in the NH environment. A formal evaluation such as this was not conducted in many of the residential settings where the LifeBio program was successfully implemented before, such as independent living and continuing care retirement communities. These settings target a population that is generally not significantly impaired, physically or cognitively, and that can afford to pay privately for housing and services. This project, however, targeted a different population of older adults, i.e., Medicaid-eligible NH residents, many of whom had significant physical and/or cognitive impairments and lacked a high level of family engagement in the project. In a population with challenges such as these and other barriers described earlier (e.g., privacy), the creation of a life story book was not as widely appealing. Even when the LifeBio program was offered to residents other than the 238 who participated in the research study, only 12 residents took advantage of it. While family involvement might have mitigated some of the barriers facing these residents, some residents did not have a "most involved family member;" in other cases, families either did not have the time to help residents participate in this endeavor or were unavailable during the period when the life story work was happening at a site. It should also be noted that there are other types of life story interventions that rely primarily on information gathered from family members, especially in the case of residents with significant cognitive impairment. For example, a memory book containing photos and simple text about a person's life can be created by a family member and help staff and others learn more about a resident's background (Bourgeois, 2013).

In terms of feasibility from the perspective of NHs, data from surveys of admission staff and administrators indicated that it would be feasible to collect this information at intake. The majority of these NH staff also indicated that using volunteers to gather life story information as a regular activity was feasible as well. However, there was no cost to the participating NHs for the life story program in this project; when asked about the feasibility of the NH paying for the intervention, its acceptability for these NHs declined markedly. Thus, findings from our sample of 11 senior management staff in NHs suggests that more NHs would be more willing to sustain the program after it ended if it was offered for free and if volunteers were available.

In terms of sustainability, overcoming barriers to implementation requires time to secure a pool of community volunteers, or needs to use other methods to facilitate the program. For example, LifeBio, Inc. had success utilizing paid student interns and staff who collected life story data in place of unpaid community volunteers; anecdotal evidence suggests that such a paid incentive and transportation for students can serve as a successful alternative when community volunteers are not available or until a volunteer pool can be assembled. LifeBio, Inc. also made several adjustments to its life story book delivery process and staff trainings, to work within the constraints of the NH environment. It offered CEUs as an incentive for participating staff, modified trainings to take place during existing in-service meetings, and simplified staff action steps for using life story information in care routines. LifeBio, Inc. explained how the program allowed administrators and NHs to meet regulatory requirements for person-centered care to assist in securing buy-in from top-level management, which was critical to successful implementation. For additional details on lessons learned and adjustments made to the program, see Appendices E and F.

Policy Recommendations and Implications

As one of the largest pilot studies implementing and evaluating life story work across a wide variety of nursing homes, this study adds to the literature on life story work and best practices in several important ways.

First, a majority of residents enjoyed participating in the program and had positive experiences with the interviewers (keeping in mind that these were residents who expressed interest in the program, wished to be involved, and had fewer cognitive deficits than are often found in the NH setting). The high frequency with which residents opted out and refused to participate in the program was a significant finding, echoing past studies and best-practice recommendations involving life story work; not everyone thinks life story work is for them, it should not be assumed all residents wish to participate, and residents' right to decline participation needs to be honored (Clarke, Hanson, & Ross, 2003; Gridley, Birks, & Parker, 2018; Gridley, Brooks, Birks, Baxter, & Parker, 2016; McKeown, Clarke, & Repper, 2006). Nevertheless, the intervention proved to be an acceptable and enjoyable activity for those with an inclination to share their own stories, allowed residents to engage in this practice on their own terms, and encouraged resident involvement in ways that were meaningful to them.

Second, evidence indicated a significant change in depressive symptomatology over time, providing some additional support for life story work's potential to improve the mental health of residents engaging in the practice (Morgan & Woods, 2010). Our results did not mirror findings from other studies that found improved resident quality of life or satisfaction with care (Elfrink, Zuidema, Kunz, & Westerhof, 2018; Grøndahl, Persenius, Bååth, & Helgesen, 2017; Subramaniam et al., 2014). Further research into the effectiveness of the LifeBio program in improving resident outcomes utilizing a randomized control or a wait-list control design are necessary to compare to residents receiving care as usual, identify the impact of NH environments on participant outcomes, and develop a stronger evidence base for life story work as a means of improving quality of care.

Third, the pilot showed strong enthusiasm from staff liaisons and administrators. There was a significant change in staff opinions about the importance of life story work over time. Initial excitement from staff about implementing the program indicated that NHs found value in utilizing life story work with residents in their care. This extends previous findings that formal and informal caregivers find the results of life story work important in learning about residents in their care (Berendonk & Caine, 2016; Eritz et al., 2016; Hewitt & Day, 2018; Kellett et al., 2010). Further research investigating why staff find this work important and its specific influences on staff perceptions of residents, empathy towards residents with dementia, and ability to provide person-centered care using the life story materials is necessary for building on the strengths of the program. Ongoing staff training on making use of the life story information could benefit both staff and residents.

Fourth, this study and the experience of implementing LifeBio across a wide variety of NHs yielded several important implications for the practice of life story work and adaptations to the program's delivery. Constraints related to resident, family, staff, and volunteer engagement in the program have been noted, and initial feedback from project liaisons and stakeholders have provided invaluable information for purposes of making modifications and streamlining the LifeBio implementation plan. Conducting further qualitative work with staff liaisons and those involved in life story work and utilizing life story materials in care routines are examples of process-level improvements that could increase acceptability of the program, maximize the visibility of life story information, and improve ways to use the materials. Continuing to work with external evaluators to tailor LifeBio's potential as a best practice in life story work, increasing the versatility of the program, reducing the administrative burden on staff at NHs, and continuing to build on the positive experiences of staff and residents are important next steps for the intervention as a potential quality improvement project in Ohio nursing homes.

Finally, developing a larger study that addresses the limitations experienced in this pilot project, including adherence to a rigorous research design and timeline, and following up with staff over a longer period after life story books have been delivered in a NH, will help determine the extent to which the findings can be generalized. Life story work can be useful to residents and staff in delivering better person-centered care, may be a source of pride for those residents who enjoy sharing a life story book with others in a NH, may help to reduce depression by promoting better engagement between residents and staff, and has feasibility as a regular activity from the perspective of senior NH management, given resources such as volunteers or dedicated project staff to help with program implementation.

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LIFEBIO, INC. PRODUCTS

The materials and interventions evaluated in this study were developed and implemented by LifeBio, Inc., unless otherwise noted, and adapted for this project. The materials were comprised of:

About Me Journal (Resource 1)– Interviews of residents are conducted using the About Me Journal that contains pre-written questions for interviewers to ask residents and a space for the interviewer to record answers. Questions in the journal cover topics including childhood location and memories, family, work history and experiences, historical life events, hobbies and interests, major life accomplishments, goals and plans for the future, and preferences for music, food, and daily activities.

Life Story Booklet – Every resident participant receives a high-quality printed life story book. These booklets are created through completing the proprietary, evidence-based About Me Journal with the help of a trained volunteer interviewer, family member, or LifeBio, Inc. paid intern or staff member.

Snapshot – Each resident participant received a framed one-page synopsis of their biography for quick reference and display.

Action Plan – Every participant received a customized one-page Action Plan that highlights their individuality: activity preferences, triggers, goals, and personal comforts. Action Plans are intended to be used primarily by NH staff to use in PCC and to plan activities that align with residents' personal preferences.

LifeBio, Inc. Booklet, Snapshot, and Action Plan

LIFE STORY INTERVIEWER TRAINING

Community volunteers, interns, and staff were recruited and trained to conduct interviews with NH residents. The 75-90 minute training (see Resource 2) covered the goals of the project and important tips for interviewing using the About Me Journal (questions relate to hometown, family, school experience, work experience, accomplishments, activities and interests, preferences, and advice/wisdom). Interview protocol was approximately one hour in length. Interviewers were instructed to ask for copies of photos for use in the Life Story Booklets.

Volunteer and intern training took place in offices, at NH sites, or via Go to Meetings

A sample one-page Action Plan and Snapshot summary

based on scheduling constraints of the volunteers and interns. Interview trainings focus on building rapport with residents and use of the About Me Journal to record the residents' personal histories.

STAFF TRAINING

The Staff "LifeBio Getting Started Training" (see Resource 3) was conducted with staff members at all locations prior to the project starting. All staff members were invited and encouraged to participate in the training. The number of participating staff members at each site ranged from a low of a single participant to a maximum of 52 participants. The average number of staff members attending trainings was 13.

The training focused on why reminiscence therapy and life story work is effective, the federal CMS regulations that LifeBio, Inc. helps support, and the process for gathering information using the About Me Journal. The training also provided instructions about the intended purpose and use of each of the products - the Life Story Booklet, one-page Snapshot, and one-page Action Plan.

LifeBio's Getting Started Training was adopted during the project to provide guidance to help direct care staff use the Snapshot summaries and Action Plans effectively. Look, Listen, and Engage became a key part of the training:

1. Look – Read the Snapshot and Action Plan;
2. Learn – Remember at least ONE new thing;
3. Engage – Use your knowledge to start a conversation ("Tell me more about…")

Continuing Education Units (CEUs) for social workers and activity directors, or certificates stating the training hours (for CNAs), were provided to staff who attended.

LifeBio anticipated conducting a follow-up staff training after the Booklets were delivered to the sites. However, this training was integrated into a LifeBio presentation of the Booklet and Snapshot to the resident by

key staff members. Helping staff honor the stories that had been collected became less of a training module and more of a guided experience.

CONDUCTING INTERVIEWS

The LifeBio, Inc. approach to interviewing residents and family members focused on empathy and understanding of the other's experiences. Specifically, LifeBio interviewers were guided to focus on signals such as:

- Do they light up when you bring up something?
- Do they close down or get quiet about a topic?
- Is it better to move on?

Interviewers were trained to gather information that was shared willingly, avoid topics that appeared to be sensitive, and create a positive experience that allowed individuals to connect safely. Approximately one hour was spent conducting each interview. The one-hour timeframe was usually adequate to provide enough information for the resident to share key background, memories, activity ideas, and preferences with the interviewer. At the conclusion of the interview, each participant was asked if they would like their photo to be taken or if they would like photos taken of things that are meaningful to them. If the resident (or a family member) was being interviewed over the phone, they were asked if there were any photographs or memorabilia that they would like to include in the Booklet.

DELIVERY AND PRESENTATION OF MATERIALS

After interviews were complete, the LifeBio, Inc. staff typed, edited, and made custom Booklets, Snapshots, and Action Plans for each participating resident. These documents were packaged inside a green presentation envelope and delivered to the NH. A staff member from LifeBio Inc. assisted the activity director or other direct care staff to present the package to the resident. With the resident's permission, snapshots were displayed in the resident's room, and the Action Plan was provided to the staff for their use in reviewing the resident's life background and for care planning ideas.

The LifeBio staff member who delivered the books to the NH assisted staff in the presentations of the books to the residents and made sure the Snapshots were read out loud in a group by the activity director or a direct care staff member (CNA, nurse) to spotlight the resident and their interests. LifeBio also ensured the staff members knew to give the Life Story Book to the resident for their and their family's enjoyment. Staff were provided with guidance regarding effective strategies to use when presenting and discussing the materials with residents (see Resource 4).

Action Plans were given to the Administrator or kept by the Activity Director for use in care planning. To protect patient privacy, the Action Plans were presented in a binder that was accessible to staff but not made public.

Appendix B: Resident, Staff, Family, and Volunteer Surveys

FOR OFFICE USE ONLY:
RESIDENT ID: _____
FAMILY/LEGAL GUARDIAN ID: _____
NURSING HOME ID: _____
INTERVIEWER ID: _____
PRE-TEST: _____ POST-TEST:_____

RESIDENT'S FULL NAME: _

NAME OF NURSING HOME: _____

DATE OF COMPLETION (MM/DD/YY): _____/_____/_____

SECOND DATE OF COMPLETION (MM/DD/YY) IF APPLICABLE: _____/_____/_____

START TIME (IN MILITARY TIME):_____:_____ (ADD 12 TO HOURS STARTING AT 1 P.M.)

Note: In Part 2, repeat questions if necessary up to a maximum of 3 times before moving to the next question. Instructions for interviewers are in ALL CAPS.

LIFEBIO PILOT STUDY FOLLOW UP RESIDENT SURVEY: PARTS ONE AND TWO COGNITIVE STATUS AND INTERVIEW (TIME 3)

Funding Source: Sponsored by the Ohio Department of Medicaid (ODM) with approval from the Centers for Medicare and Medicaid Services (CMS)

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LIFEBIO, INC.
UNIVERSAL HEALTH CARE ACTION NETWORK OF OHIO

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LIFEBIO STUDY RESIDENT SURVEY—PART 1

SECTION I: IDENTIFYING INFORMATION

I1 DATA COLLECTION POINT	I2 NURSING HOME ID #	I3 INTERVIEWER ID #	I4 RESIDENT ID #
1 2	_____	____	_____

I5 FAMILY/LEGAL GUARDIAN ID #:	I6 TODAY'S DATE	I7 START TIME (MILITARY)
_____	MM DD YYYY _ /__ /	_ : _

Please write in respondent ID here				

BRIEF INTERVIEW FOR MENTAL STATUS (BIMS)

ASK RESIDENT: I am going to say three words for you to remember. Please repeat the words after I have said all three. The words are: **sock, blue, and bed**. Now tell me the three words.

BIMS1 NUMBER OF WORDS REPEATED AFTER FIRST ATTEMPT

- ○ 0 — NONE
- ○ 1 — ONE
- ○ 2 — TWO
- ○ 3 — THREE

AFTER THE RESIDENT'S FIRST ATTEMPT, REPEAT THE WORDS USING CUES ("sock, something to wear; blue, a color; bed, a piece of furniture"). YOU MAY REPEAT THE WORDS UP TO TWO MORE TIMES.

ASK RESIDENT: Please tell me what year it is right now.

BIMS2 ABLE TO REPORT CORRECT YEAR

- ○ 0 — MISSED BY > 5 YEARS
- ○ 1 — MISSED BY 2-5 YEARS
- ○ 2 — MISSED BY 1 YEAR
- ○ 3 — CORRECT

ASK RESIDENT: What month are we in right now?

BIMS3 ABLE TO REPORT CORRECT MONTH

- ○ 0 — MISSED BY > 1 MONTH
- ○ 1 — MISSED BY 6 DAYS TO 1 MONTH
- ○ 2 — ACCURATE WITHIN 5 DAYS

ASK RESIDENT: What day of the week is today?

BIMS4 ABLE TO REPORT CORRECT DAY OF THE WEEK

- ○ 0 — INCORRECT OR NO ANSWER
- ○ 1 — CORRECT

ASK RESIDENT: Let's go back to an earlier question. What were those three words that I asked you to repeat? IF UNABLE TO REMEMBER A WORD, GIVE CUE ("something to wear; a color; a piece of furniture") FOR THAT WORD.

BIMS5 ABLE TO RECALL SOCK

- ○ 0 — NO, COULD NOT RECALL
- ○ 1 — YES, AFTER CUEING ("SOMETHING TO WEAR")
- ○ 2 — YES, NO CUE REQUIRED

BIMS6 ABLE TO RECALL BLUE

- ○ 0 — NO, COULD NOT RECALL
- ○ 1 — YES, AFTER CUEING ("A COLOR")
- ○ 2 — YES, NO CUE REQUIRED

BIMS7 ABLE TO RECALL BED

- ○ 0 — NO, COULD NOT RECALL
- ○ 1 — YES, AFTER CUEING ("A PIECE OF FURNITURE")
- ○ 2 — YES, NO CUE REQUIRED

BIMS8 SUMMARY OF SCORES: PLEASE ADD UP THE TOTAL SCORES FROM QUESTIONS BIMS1-7; CHECK THE BOX BELOW THAT MATCHES THE RESIDENT'S SCORE

- ○ 13-15: COGNITIVELY INTACT
- ○ 08-12: MODERATELY IMPAIRED
- ○ 00-07: SEVERE IMPAIRMENT

IF RESIDENT'S SCORE IN BIMS8 IS:

- **08-15: PROCEED TO PART 2, SECTION A, OF THE RESIDENT SURVEY. DO NOT COMPLETE INTERVIEW ADMINISTRATION, PART 1.**
- **00-07: DO NOT PROCEED TO PART 2 OF THE RESIDENT SURVEY. THANK THE RESIDENT FOR HIS/HER TIME AND TAKE THE RESIDENT BACK TO HIS/HER ROOM OR ASK A STAFF PERSON TO HELP WITH DOING THIS. THEN COMPLETE SECTION III BELOW.**

Please write in respondent ID here				

SECTION III: INTERVIEW ADMINISTRATION— COMPLETE ONLY IF BIMS SCORE IS LESS THAN 8

X1 INTERVIEW STATUS

- ○ INCOMPLETE
- ○ COMPLETE

X2 REASON WHY INTERVIEW IS INCOMPLETE (IF APPLICABLE)

- ○ RESIDENT FATIGUE
- ○ UNABLE TO RESPOND TO QUESTIONS / FAILED THE BIMS
- ○ REFUSAL TO CONTINUE
- ○ NECESSARY CLINICAL CARE
- ○ RESIDENT ILLNESS
- ○ OTHER

X3 ASSISTANCE WITH INTERVIEW (IF UNAVOIDABLE)

- ○ FAMILY MEMBER
- ○ VOLUNTEER
- ○ CUSTODIAN/GUARDIAN
- ○ OTHER

X4 END TIME (MILITARY)	X5 START TIME 2 (MILITARY) *IF INTERVIEW WAS INTERRUPTED AND RESTARTED*	X6 END TIME 2 (MILITARY) *IF INTERVIEW WAS INTERRUPTED AND RESTARTED*
_ : _	_ : _	_ : _

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LIFEBIO STUDY RESIDENT SURVEY—PART 2

SECTION I: IDENTIFYING INFORMATION [FOR OFFICE USE ONLY]

I1 DATA COLLECTION POINT	I2 NURSING HOME ID #	I3 INTERVIEWER ID #	I4 RESIDENT ID #	I5 FAMILY/LEGAL GUARDIAN ID #:	I6 TODAY'S DATE M M / D D / Y Y Y Y	I7 START TIME (MILITARY)
1	_____	____	_____	_____	_ /__ /	_ : _
2						

SECTION A: DEMOGRAPHICS

I'd like to ask you some questions about your background.

A1 How long have you lived here?

- ○ LESS THAN 1 YEAR
- ○ 1 TO 5 YEARS
- ○ MORE THAN 5 YEARS
- ○ DON'T REMEMBER
- ○ REFUSED TO ANSWER

A2 How old are you? (ROUND TO THE NEAREST YEAR)

_____

A3 What is your highest level of education?

- ○ LESS THAN A HIGH SCHOOL DIPLOMA
- ○ HIGH SCHOOL DIPLOMA
- ○ SOME COLLEGE, NO DEGREE
- ○ ASSOCIATE'S DEGREE
- ○ BACHELOR'S DEGREE
- ○ MASTER'S DEGREE OR OTHER POST-GRADUATE DEGREE
- ○ DON'T KNOW/REFUSED TO ANSWER

IF RESPONDENT SAYS 12TH GRADE OR ANY COLLEGE, ASK "Did you graduate?"

SECTION B: FRIENDSHIP AND SOCIAL SUPPORTS

B1 Do you have children, other relatives (E.G., GRANDCHILDREN, NIECES/NEPHEWS) or friends who contact you by visiting or calling?

- ○ YES
- ○ NO (IF 'NO', SKIP TO SECTION C)

Please write in respondent ID here | | | | |

SECTION C: ACTIVITIES OF DAILY LIVING

SHOW RESPONDENT RESPONSE CARD 1 I'd like to ask you about some of your activities of daily living, things that we all need to do as a part of our daily lives. I would like to know if you can do these activities **without any help at all**, or if you need **some help to do them,** or **if you can't do them at all. Can you:**		**Without any help**	**With some help**	**Com-pletely Unable**	DON'T KNOW/ REFUSED TO AN-SWER
C1	**Eat?** (*WITH SOME HELP INCLUDES NEEDS HELP WITH CUTTING, ETC.)*	○	○	○	○
C2	**Dress and undress yourself?** (WITH SOME HELP INCLUDES CHOOSING AND PUTTING ON / TAKING OFF CLOTHING)	○	○	○	○
C3	**Take care of your own appearance, for example combing your hair and (FOR MEN) shaving?** (WITH SOME HELP MEANS NEEDS HELP WITH SHAMPOOING HAIR, TRIM-MING NAILS)	○	○	○	○
C4	**Walk?** *(WITHOUT HELP INCLUDES USING A CANE; WITH SOME HELP IN-CLUDES GETTING HELP FROM A PERSON OR WITH THE USE OF A WALKER, CRUTCHES, ETC.)*	○	○	○	○
C5	**Get in and out of bed?** *(WITH SOME HELP INCLUDES GETTING HELP FROM A PERSON OR A DEVICE)*	○	○	○	○
C6	**Take a bath or shower?** *(WITH SOME HELP INCLUDES GETTING IN AND OUT OF THE TUB OR NEEDING SPECIAL ATTACHMENTS ON THE TUB)*	○	○	○	○

SECTION D: PHYSICAL HEALTH AND WELL-BEING

PRESENT RESPONSE CARD 2

D1 In general, how would you rate your overall physical health?

- ○ Excellent
- ○ Very good
- ○ Good
- ○ Fair
- ○ Poor
- ○ DON'T KNOW/REFUSED TO ANSWER

SECTION E: MENTAL HEALTH AND WELL-BEING

A. SELF-RATED MENTAL HEALTH

EA1 In general, how would you rate your overall mental or emotional health?

- ○ Excellent
- ○ Very good
- ○ Good
- ○ Fair
- ○ Poor
- ○ DON'T KNOW/REFUSED TO ANSWER

Please write in respondent ID here				

B. DEPRESSION

PRESENT RESPONSE CARD 3

I am going to ask you some questions about your mood and feelings over the past 2 weeks.

PATIENT HEALTH QUESTIONNAIRE *Over the past two weeks, how often have you been bothered by any of the following problems?*		Not at all	Several days	More than half the days	Nearly every day	DON'T KNOW/ REFUSED TO ANSWER
EB1	Little interest or pleasure in doing things	○	○	○	○	○
EB2	Feeling down, depressed or hopeless	○	○	○	○	○
EB3	Trouble falling asleep, staying asleep, or sleeping too much	○	○	○	○	○
EB4	Feeling tired or having little energy	○	○	○	○	○
EB5	Poor appetite or overeating	○	○	○	○	○
EB6	Feeling bad about yourself- or that you are a failure or have let yourself or your family down	○	○	○	○	○
EB7	Trouble concentrating on things, such as reading the news-paper or watching television	○	○	○	○	○
EB8	Moving or speaking so slowly that other people could have noticed. Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	○	○	○	○	○

C. HAPPINESS

PRESENT RESPONSE CARD 4

Taking all things together, how happy are you with your life as a whole these days?

EC1 **Would you say you are very happy, somewhat happy, somewhat unhappy or very unhappy?**

- ○ Very happy
- ○ Somewhat Happy
- ○ Somewhat Unhappy
- ○ Very Unhappy
- ○ DON'T KNOW/REFUSED TO ANSWER

SECTION F: PERCEIVED QUALITY OF LIFE

PRESENT RESPONSE CARD 5

A. SINGLE ITEM – GLOBAL QoL:

Thinking about both the good and bad things that make up your quality of life, how would you rate the quality of your life as a whole?

		Very good	Good	All Right	Bad	Very bad	DON'T KNOW / REFUSED ANSWER
FA1	Your quality of life as a whole is:	○	○	○	○	○	○

B. OPQOL-Brief PRESENT RESPONSE CARD 6

Please select the response that best describes you/your views from the following options (LIST OPTIONS FROM 'STRONGLY AGREE' TO 'STRONGLY DISAGREE'). There are no right or wrong answers.

		Strongly Agree	Agree	Neither agree nor disagree	Disa-gree	Strongly Disagree	DON'T KNOW / RE-FUSED TO ANSWER
FB1	I enjoy my life overall	○	○	○	○	○	○
FB2	My family, friends or nursing home staff would help me if needed	○	○	○	○	○	○
FB3	I can do as I please here	○	○	○	○	○	○
FB4	I take life as it comes and make the best of things	○	○	○	○	○	○

Please write in respondent ID here | | | | |

SECTION G: PERCEIVED USEFULNESS OF LIFE HISTORIES

I am going to read a statement. Please select the response that best describes you/your views from the following options (LIST OPTIONS FROM 'STRONGLY AGREE' TO 'STRONGLY DISAGREE') There are no right or wrong answers.

		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree	DON'T KNOW / REFUSED TO ANSWER
G1	It is important to me that the staff knows about my life story. By life story, we mean what you did when you were younger, how many children you had, and other important details about your life.	○	○	○	○	○	○
G2	The staff who take care of me are interested in learning about my life story.	○	○	○	○	○	○
G3	The nursing home staff will provide better care to me if they know my life story.	○	○	○	○	○	○

SECTION QI: LIFEBIO QUALITY IMPROVEMENT

I'd like to ask about your experience with the life story program. For the following questions, say "yes" if you agree with them, and "no" if you disagree. There are no right or wrong answers:

		Yes	No	DON'T KNOW / REFUSED TO ANSWER
QI1.	Did you enjoy telling your life story?	○	○	○
QI2	Did you have enough time with the interviewer to share your life story?	○	○	○
QI3.	When you got your life story book, did you share it with family and friends?	○	○	○
QI4.	When you got your life story book, did you share it with the staff who care for you?	○	○	○
QI5.	Do you think the nursing home staff are providing better care to you after they know your life story?	○	○	○
QI6.	Do you think it is important that your life story book was created?	○	○	○
QI7.	Would you recommend the life story program to other nursing home residents?	○	○	○
QI8	Did you like your life story book?	○	○	○
QI9	Is your one page life story summary displayed inside or outside of your room?	○	○	○

Please write in respondent ID here				

SECTION H: RESIDENT SATISFACTION—PRESENT RESPONSE CARD 7

Finally, I'd like to ask you some questions about your experience living at this nursing home.
AFTER EACH QUESTION, STATE THE RESPONSE CATEGORIES, "Generally yes." AND "Generally, no." MARK THE RESPONDENT'S ANSWER.

		Generally, yes	Generally, no	DON'T KNOW / REFUSED TO ANSWER
H1	Are you given plenty of opportunities to do things that are meaningful to you?	○	○	○
H2	Are your preferences about daily routines carried out (e.g., time and place for meals and time and type of bath)?	○	○	○
H3	Do the people who work here know what you like and don't like?	○	○	○
H4	Do the people who care for you treat you gently?	○	○	○
H5	Do the people who care for you do things the way you want them done?	○	○	○
H6	Do the people who work here go above and beyond to give you a good life?	○	○	○
H7	Are you friends with anyone who lives here (PROBE (IF NEEDED): Is there anyone you enjoy spending time with?)?	○	○	○
H8	Would you highly recommend this nursing home to a family member or friend?	○	○	○

SECTION X: INTERVIEW ADMINISTRATION

X1 INTERVIEW STATUS

- ○ INCOMPLETE
- ○ COMPLETE

X2 REASON WHY INTERVIEW IS INCOMPLETE (IF APPLICABLE)

- ○ RESIDENT FATIGUE
- ○ UNABLE TO RESPOND TO QUESTIONS
- ○ REFUSAL TO CONTINUE
- ○ NECESSARY CLINICAL CARE
- ○ RESIDENT ILLNESS
- ○ OTHER

X3 ASSISTANCE WITH INTERVIEW (IF UNAVOIDABLE)

- ○ FAMILY MEMBER
- ○ VOLUNTEER
- ○ CUSTODIAN/GUARDIAN
- ○ OTHER

X4 END TIME (MILITARY)	X5 START TIME 2 (MILITARY) *IF INTERVIEW WAS INTERRUPTED AND RESTARTED*	X6 END TIME 2 (MILITARY) *IF INTERVIEW WAS INTERRUPTED AND RESTARTED*
_ : _	_ : _	_ : _

Please write in respondent ID here				

SECTION I: CONCLUSION

Before we finish, I have one final question. Is there anything else you would like to tell me? WRITE ANSWER IN THE BOX BELOW.

Thank you for taking the time to complete this interview and your participation in the project!

BENJAMIN ROSE
INSTITUTE ON AGING
SERVICE • RESEARCH • ADVOCACY

RESIDENT'S FULL NAME: _____

NAME OF NURSING HOME: _____

INTERVIEW COMPLETED WITH FAMILY PARTICIPATION:_____YES _____NO

DATE OF COMPLETION (MM/DD/YYYY):_____/_____/_____

Instructions for interviewers are in ALL CAPS. Read sentence case to Respondents.

LIFEBIO PILOT STUDY

OPENING UP THE LIFE STORY PROJECT TO ALL NURSING HOME RESIDENTS

Funding Source: Sponsored by the Ohio Department of Medicaid (ODM) with approval from the Centers for Medicare and Medicaid Services (CMS)

COLLABORATING PARTNERS: OHIO COLLEGES OF MEDICINE GOVERNMENT RESOURCE CENTER
LIFEBIO, INC.
UNIVERSAL HEALTH CARE ACTION NETWORK OF OHIO
BENJAMIN ROSE INSTITUTE ON AGING

LIFEBIO STUDY RESIDENT QUALITY IMPROVEMENT SURVEY
ADMINISTRATIVE INFORMATION

IDENTIFYING INFORMATION [FOR GRC OFFICE USE ONLY]

NURSING HOME ID# - _____

RESIDENT ID #: _____

B11

QI SURVEY QUESTIONS

I would like to ask you some questions about your experience with the life story program….

LIFEBIO QUALITY IMPROVEMENT SURVEY - RESIDENT				
For the following questions, say "yes" if you agree with them, and "no" if you disagree:		**Yes (1)**	**No (0)**	**DON'T KNOW / REFUSED TO ANSWER (999)**
Q1.	**Did you enjoy telling your life story?**	☐	☐	☐
Q2.	**Did you have enough time with the interviewer to share your life story?**	☐	☐	☐
Q3.	**When you get your life story book, will you share it with family and friends?**	☐	☐	☐
Q4.	**When you get your life story book, will you share it with the staff who care for you?**	☐	☐	☐
Q5.	**Do you think the nursing home staff will provide better care to you after they know your life story?**	☐	☐	☐
Q6.	**Do you think it is important that your life story book is being created?**	☐	☐	☐
Q7.	**Would you recommend the life story program to other nursing home residents?**	☐	☐	☐

DEMOGRAPHICS

I'd like to ask you some questions about your background

A1 How long have you lived here?

- ○ LESS THAN 1 YEAR
- ○ 1 TO 5 YEARS
- ○ MORE THAN 5 YEARS
- ○ DON'T REMEMBER
- ○ REFUSED TO ANSWER

A2 What is your age? (ROUND TO THE NEAREST YEARS) _____

A3 What is your highest level of education? (MARK ONE)

- ○ Less than a high school diploma
- ○ High school diploma
- ○ Some college, no degree
- ○ Associate's degree
- ○ Bachelor's degree
- ○ Master's degree or other post-graduate degree
- ○ Don't Know – Refused to Answer

A4 What is your gender? (MARK ONE)

- ○ Male
- ○ Female
- ○ Other (PLEASE SPECIFY :_____)

A5 What is your race? (MARK ALL THAT APPLY)

- ○ American Indian or Alaska Native
- ○ Asian
- ○ Black or African American
- ○ Hispanic or Latino
- ○ Native Hawaiian or Other Pacific Islander
- ○ White
- ○ Other (PLEASE SPECIFY:_____)

COMMENTS

Before we finish, I have one final question:

Do you have any recommendations for improving the life story program? (Write the answer below).

Thank you for taking the time to complete this survey and participating in the LifeBio Pilot Program!

IDENTIFYING INFORMATION [FOR GRC OFFICE USE ONLY]

NURSING HOME ID# - _____

RESIDENT ID #: _____

B13

FOR OFFICE USE ONLY:
STAFF ID: _____
NURSING HOME ID: _____
PRE-TEST: _____ POST-TEST:_____

YOUR FULL NAME (PLEASE PRINT):_____

NAME OF NURSING HOME: _____

DATE YOU COMPLETED THIS SURVEY (MM/DD/YY):_____/_____/_____

LIFEBIO PILOT STUDY

STAFF FOLLOW-UP SURVEY (TIME 2)

Funding Source: Sponsored by the Ohio Department of Medicaid (ODM) with approval from the Centers for Medicare and Medicaid Services (CMS)

PROJECT TEAM MEMBERS: FARIDA K. EJAZ, PH.D.

MIRIAM ROSE, M.ED.

BRIAN POLK, M.A.

MINZHI YE, M.A.

COURTNEY REYNOLDS, M.A., M.S.S.A.

JENNA LOVASZ B.S.

KATE MCCARTHY

CENTER FOR RESEARCH AND EDUCATION

COLLABORATING PARTNERS: OHIO COLLEGES OF MEDICINE GOVERNMENT RESOURCE CENTER
LIFEBIO INC.
UNIVERSAL HEALTH CARE ACTION NETWORK

SECTION I OF THE SURVEY IS FOR OFFICE USE ONLY

PLEASE PROCEED TO <u>SECTION B</u> AFTER YOU HAVE COMPLETED THE CONSENT FORM. IF YOU CHOOSE THE 'OTHER' RESPONSE TO A QUESTION, PLEASE WRITE A SHORT DESCRIPTION ON THE LINE TO THE RIGHT OF IT.

BENJAMIN ROSE INSTITUTE ON AGING
SERVICE • RESEARCH • ADVOCACY

LIFEBIO STUDY STAFF SURVEY

SECTION I: IDENTIFYING INFORMATION

SECTION I IS FOR OFFICE USE ONLY.

PLEASE PROCEED TO SECTION B AFTER YOU HAVE COMPLETED THE COVER PAGE AND CONSENT FORM

I1 DATA COLLECTION POINT	I2 NURSING HOME ID #	I3 STAFF ID #	I4 TODAY'S DATE
			MM DD YYYY
2	_____	_____	/__ / _

SECTION B: BACKGROUND INFORMATION

B1 What is your gender?

○ Male ○ Female ○ Other

B2 How old are you? (ROUND TO THE NEAREST YEAR)

_____

B3 What is your highest level of education? (MARK ONE)

- ○ Less than a high school diploma
- ○ High school diploma
- ○ Some college, no degree
- ○ Associate's degree
- ○ Bachelor's degree
- ○ Master's degree or other post-graduate degree

B4 What is your race? (MARK ALL THAT APPLY)

- ○ American Indian or Alaska Native
- ○ Asian
- ○ Black or African American
- ○ Hispanic or Latino
- ○ Native Hawaiian or Other Pacific Islander
- ○ White

OFFICE USE ONLY— Please write in staff ID here				

SECTION C: EMPLOYMENT INFORMATION

C1 What is your job title? (MARK ONE)

- ○ Nursing Aide / Assistant
- ○ Admissions Staff
- ○ Administrator
- ○ Assistant Administrator
- ○ Activities Staff
- ○ Licensed Nurse
- ○ Social Worker
- ○ Physical/Occupational Therapist
- ○ Other _

C2 Are you licensed or certified? (MARK ALL THAT APPLY)

- ○ STNA
- ○ SWA/LSW/LISW/LISW-S
- ○ LNHA
- ○ LPN/RN
- ○ AAC/ADC/ADPC/ACC/HCC
- ○ OTHER _
- ○ NOT LICENSED OR CERTIFIED

C3 How many years have you worked in nursing homes? (ROUND TO THE NEAREST YEAR)

C4 How many years have you worked in this particular nursing home? (ROUND TO THE NEAREST YEAR)

_____

C5 Are you considered full-time or part-time?

- ○ Full-time
- ○ Part-time
- ○ PRN (ON AN AS-NEEDED BASIS)
- ○ Other _

SECTION D: JOB SATISFACTION

A. DIRECT CARE WORKER JOB SATISFACTION SCALE **How satisfied are you with...**		**Very dis-satisfied**	**Dissatis-fied**	**Satisfied**	**Very Satisfied**
DA1	The working conditions here?	○	○	○	○
DA2	The recognition you get for your work?	○	○	○	○
DA3	The attention paid to the suggestions you make?	○	○	○	○
DA4	Your pay?	○	○	○	○
DA5	Your fringe benefits (health insurance, paid time off, etc.)?	○	○	○	○
DA6	The amount of time you have to get your job done?	○	○	○	○
DA7	The teamwork between staff to improve care provided to residents?	○	○	○	○
DA8	The way management and staff work together?	○	○	○	○
DA9	The way you are included in resident care plan meetings?	○	○	○	○
DA10	If a friend or family member was thinking about taking a job at the nursing home where you work, and asked your advice, would you recommend it?	○ **Yes**		○ **No**	

OFFICE USE ONLY—Please write in staff ID here				

BENJAMIN ROSE INSTITUTE ON AGING
SERVICE • RESEARCH • ADVOCACY

LIFEBIO STUDY STAFF SURVEY

B. JOB TURNOVER

DB1 **Have you considered looking for another job in the past two months?** ○ **Yes** ○ **No**

DB2 **If you decided to leave the nursing home where you work now, what would be your reason(s) for leaving? (MARK ALL THAT APPLY)**

- ○ Going back to school / Furthering education
- ○ Problems with clients / residents
- ○ Inadequate benefits
- ○ Problems with co-workers
- ○ Lack of quality time with residents
- ○ Problems with supervisor
- ○ Not enough hours / pay
- ○ Retirement
- ○ Not feeling valued / respected
- ○ Other _

SECTION E: PERCEIVED USEFULNESS OF A RESIDENT'S LIFE HISTORY

Please read the following statements and select the response that best describes your views from the following options. There are no right or wrong answers.

		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
E1	**It is important to me to know about the residents' life stories. By life stories, we mean what they did when they were younger, how many children they have, and other important details from their lives.**	○	○	○	○	○
E2	**I am not interested in learning about the residents' life stories.**	○	○	○	○	○
E3	**I would provide better care to the residents knowing their life stories.**	○	○	○	○	○

SECTION QI: LIFEBIO QUALITY IMPROVEMENT QUESTIONS - STAFF PERSPECTIVE

Please read the following statements and select the response that best describes your views from the following

		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
QI1	**I used the information from the residents' life stories in their care plans.**	○	○	○	○	○
QI2	**I enjoyed learning the life stories of residents.**	○	○	○	○	○
QI3	**It's important that the residents' life stories were created.**	○	○	○	○	○
QI4	**The quality of the life story booklets were excellent.**	○	○	○	○	○
QI5	**The quality of the one page life story summaries were excellent.**	○	○	○	○	○
QI6	**The one page life story summaries were very useful in my work .**	○	○	○	○	○
QI7	**I have enough time to use the information from the one page summary of residents' life stories when talking to residents**	○	○	○	○	○
QI8	**I would recommend the resident life story program to other nursing homes**	○	○	○	○	○

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SECTION F : THE RESIDENTS YOU CARE FOR (DIRECT CARE STAFF ONLY)

F1 **On average, how many residents are you responsible for in one shift? (NUMBERS ONLY)**

		Never	Hardly ever	Some of the time	Most of the time
F2	How often are the residents you care for consistently assigned to your care?	○	○	○	○
F3	How often do the residents show respect for you?	○	○	○	○
F4	How often do the residents act friendly to you?	○	○	○	○
F5	How often do the residents act rude or insulting to you?	○	○	○	○

SECTION G: SUPPLEMENTAL FORM

COMPLETE THIS SECTION ONLY IF YOU ARE AN ADMINISTRATOR, ASSISTANT ADMINISTRATOR, OR ADMISSIONS COORDINATOR

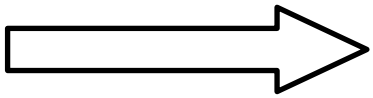
G1 **Does your nursing home currently collect data on residents life histories during the admissions/intake process?**

○ YES (GO TO QUESTION G3)
○ NO (GO TO QUESTION G2)
○ DON'T KNOW (GO TO QUESTION G2)

Please read the following questions and select the response that best reflects your options/views.

		Not feasible	Somewhat feasible	Very feasible
G2	How feasible do you think it is to collect data on a resident's life history during the admissions/intake process?	○	○	○
G3	If volunteers were provided to gather residents' life histories, how feasible would it be to make this a regular activity/program offered to residents in your nursing home?	○	○	○
G4	If the nursing home had to pay approximately $100 per resident and volunteer to gather residents' life histories, how feasible would it be to make this a regular activity/program offered to residents in your nursing home?	○	○	○

PLEASE COMPLETE THE CONCLUSION SECTION ON THE NEXT PAGE



OFFICE USE ONLY—Please write in staff ID here				

SECTION H: CONCLUSION

Is there anything else you would like us to know about your work experience? Please let us know in the box below.

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY.

YOUR PARTICIPATION IN THIS PROJECT PROVIDES VALUABLE INFORMATION FOR IMPROVING THE LIVES OF NURSING HOME RESIDENTS.

PLEASE RETURN YOUR COMPLETED SURVEY WITHIN THE WEEK AND SEND TO BENJAMIN ROSE INSTITUTE ON AGING USING THE ENCLOSED ENVELOPE AFTER YOU HAVE SEALED IT.

ONCE AGAIN, THANK YOU FOR YOUR TIME AND PARTICIPATION.

BENJAMIN ROSE
INSTITUTE ON AGING
SERVICE • RESEARCH • ADVOCACY

FOR OFFICE USE ONLY:
FAMILY/LEGAL GUARDIAN ID: _____
RESIDENT ID: _____
NURSING HOME ID: _____
PRE-TEST: _____ POST-TEST:_____

YOUR FULL NAME (PLEASE PRINT)_____

FULL NAME OF YOUR RELATIVE/WARD (PLEASE PRINT): _____

NAME OF YOUR RELATIVE/WARD'S NURSING HOME: _

YOUR RELATIVE/WARD'S MONTH AND DAY OF BIRTH (MM/DD):_____/_____

DATE YOU COMPLETED THIS SURVEY (MM/DD/YY):_____/_____/_____

LIFEBIO PILOT STUDY

FAMILY AND LEGAL GUARDIAN SURVEY:

CONSENT & FOLLOW-UP SURVEY

Funding Source: Sponsored by the Ohio Department of Medicaid (ODM) with approval from the Centers for Medicare and Medicaid Services (CMS)

PROJECT TEAM MEMBERS: FARIDA K. EJAZ, PH.D.

MIRIAM ROSE, M.ED.

BRIAN POLK, MA

MINZHI YE, M.A.

COURTNEY REYNOLDS, M.A., M.S.S.A.

JENNA LOVASZ B.S.

KATE MCCARTHY

CENTER FOR RESEARCH AND EDUCATION

COLLABORATING PARTNERS: OHIO COLLEGES OF MEDICINE GOVERNMENT RESOURCE CENTER
LIFEBIO INC.
UNIVERSAL HEALTH CARE ACTION NETWORK

SECTION I OF THE SURVEY IS FOR OFFICE USE ONLY

PLEASE PROCEED TO <u>SECTION B</u> AFTER YOU HAVE COMPLETED THE CONSENT FORM. IF YOU CHOOSE THE 'OTHER' RESPONSE TO A QUESTION, PLEASE WRITE A SHORT DESCRIPTION ON THE LINE TO THE RIGHT OF IT.

BENJAMIN ROSE INSTITUTE ON AGING
SERVICE • RESEARCH • ADVOCACY

LIFEBIO STUDY FAMILY AND GUARDIAN SURVEY

SECTION I: IDENTIFYING INFORMATION

SECTION I IS FOR OFFICE USE ONLY.

PLEASE PROCEED TO SECTION B AFTER YOU HAVE COMPLETED THE COVER PAGE

I1 DATA COLLECTION POINT	I2 NURSING HOME ID #	I3 RESIDENT ID #	I4 FAMILY/LEGAL GUARDIAN ID #	I5 TODAY'S DATE MM DD YYYY
①				
②	_____	_____	_____	__ /__ / __

SECTION B: BACKGROUND INFORMATION

B1 What is your gender?

○ MALE ○ FEMALE ○ OTHER

B2 How old are you? (ROUND TO THE NEAREST YEAR)

B3 What is your highest level of education?

- ○ Less than a high school diploma
- ○ High school diploma
- ○ Some college, no degree
- ○ Associate's degree
- ○ Bachelor's degree
- ○ Master's degree or other post-graduate degree

B4 What is your race? (MARK ALL THAT APPLY)

- ○ American Indian or Alaska Native
- ○ Asian
- ○ Black or African American
- ○ Hispanic or Latino
- ○ Native Hawaiian or Other Pacific Islander
- ○ White

Please write in respondent ID here				

B5 What is your relationship to your relative (ward) who lives in the nursing home?

- ○ Spouse
- ○ Child
- ○ Grandchild
- ○ Niece/Nephew
- ○ Son-/Daughter-in-Law
- ○ Brother/Sister
- ○ Friend
- ○ Parent
- ○ Guardian
- ○ Other _

B6 How long has your relative (ward) lived in the nursing home where he/she currently resides?

- ○ Less than 1 year
- ○ 1 to 5 years
- ○ More than 5 years
- ○ Don't know

B7 On average, how often do you visit your relative (ward)?

- ○ Daily
- ○ Several times per week
- ○ Once a week
- ○ Two or three times per month
- ○ Once a month
- ○ Few times a year

SECTION C: FAMILY SATISFACTION

Please complete the next section on your satisfaction with the care provided to your relative (ward) in the nursing home. Your relative (ward) will be referred to as "the resident" in this section.

		Definitely no	Probably no	Probably yes	Definitely yes	Don't know / Not Applicable
C1	Does the resident have plenty of opportunities to do things that are meaningful to him/her?	○	○	○	○	○
C2	Are the resident's preferences about daily routine carried out (e.g., time and place for meals and time and type of bath)?	○	○	○	○	○
C3	Do the staff know what the resident likes and doesn't like?	○	○	○	○	○
C4	Do the staff go above and beyond to give your resident a good life?	○	○	○	○	○
C5	Would you highly recommend this care facility to a family member or friend?	○	○	○	○	○

SECTION D: PERCEIVED USEFULNESS OF LIFE HISTORIES

Please select the response that best describes you/your views from the following options. There are no right or wrong answers.

		Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree
D1	It is important to me that the staff knows about my relative's (ward's) life story. By life story, we mean what she/he did when she/he was younger, how many children she/he has, and other important details from her/his life.	○	○	○	○	○
D2	The staff who take care of my relative (ward) are not interested in learning about her/his life story.	○	○	○	○	○
D3	The nursing home staff would provide better care to my relative (ward) if they knew her/his life story.	○	○	○	○	○

PLEASE COMPLETE THE CONCLUSION SECTION ON THE LAST PAGE

Please write in respondent ID here				

SECTION E: CONCLUSION

Is there anything else you would like us to know about your experience? Please let us know in the box below.

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY.

YOUR PARTICIPATION IN THIS PROJECT PROVIDES VALUABLE INFORMATION FOR IMPROVING THE LIVES OF NURSING HOME RESIDENTS.

BENJAMIN ROSE
INSTITUTE ON AGING
SERVICE • RESEARCH • ADVOCACY

FOR OFFICE USE ONLY:

VOLUNTEER ID: _____
NURSING HOME ID: _____

YOUR FULL NAME (PLEASE PRINT):_____

DATE YOU COMPLETED THIS SURVEY (MM/DD/YY):_____/_____/_____

LIFEBIO PILOT STUDY

VOLUNTEER SURVEY

Funding Source: Sponsored by the Ohio Department of Medicaid (ODM) with approval from the Centers for Medicare and Medicaid Services (CMS)

PROJECT TEAM MEMBERS: FARIDA K. EJAZ, PH.D.

MIRIAM ROSE, M.ED.

BRIAN POLK, M.A

MINZHI YE, M.A

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KATE MCCARTHY

CENTER FOR RESEARCH AND EDUCATION

BENJAMIN ROSE INSTITUTE ON AGING

COLLABORATING PARTNERS: OHIO COLLEGES OF MEDICINE GOVERNMENT RESOURCE CENTER

LIFEBIO

UNIVERSAL HEALTH CARE ACTION NETWORK

PLEASE START WITH THE CONSENT FORM AND SIGN BOTH COPIES. KEEP ONE COPY OF THE CONSENT FORM FOR YOURSELF. MAIL THE OTHER ALONG WITH YOUR SURVEY TO THE BENJAMIN ROSE INSTITUTE ON AGING USING THE ATTACHED POSTAGE PAID ENVELOPE.

SECTION B: BACKGROUND INFORMATION

1	**What is your gender?**			
	☐ MALE (0)	☐ FEMALE (1)	☐ 2 OTHER	
2	**How old are you?_____(PLEASE ROUND TO THE NEAREST YEAR)**			
3	**What is your highest level of education?**			
	☐**1**	Less than a high school diploma	☐4	Associate's degree
	☐**2**	High school diploma	☐5	Bachelor's degree
	☐**3**	Some college, no degree	☐6	Master's degree or other post-graduate degree
4	**What is your race? (CHECK ALL THAT APPLY)**			
	☐**1**	American Indian or Alaska Native	☐**1**	Hispanic or Latino
	☐**1**	Asian	☐1	Native Hawaiian or Other Pacific Islander
	☐**1**	Black or African American	☐**1**	White
5	**In what nursing homes did you collect resident life stories as part of the LifeBio Pilot Project? Please print the names of each nursing home in the lines below.**			
6	**Are you a student?**			
	☐ YES → GO TO QUESTION 7 (1)		☐ NO → GO TO SECTION C (0)	
7	**Did you receive credit for volunteering?**			
	☐ YES (1)		☐ NO (0)	

SECTION C: PERCEIVED USEFULNESS OF LIFEBIO AND QUALITY IMPROVEMENT

Please select the response that best describes you/your views from the following options. There are no right or wrong answers.

		Strongly Agree (5)	Agree (4)	Neither agree nor disagree (3)	Disagree (2)	Strongly Disagree (1)
1	It is important to me to know about the residents' life stories at the nursing home(s) where I volunteered. By life stories, we mean what they did when they were younger, how many children they had, and other important details from their lives.	☐	☐	☐	☐	☐
2	I am not interested in learning about the residents' life stories at the nursing home(s) where I volunteered.	☐	☐	☐	☐	☐
3	I would be a better volunteer if I knew the residents' life stories at the nursing home(s) where I volunteer.	☐	☐	☐	☐	☐
4	I enjoyed hearing the life stories of residents.	☐	☐	☐	☐	☐
5	I had enough time with residents to gather their life stories.	☐	☐	☐	☐	☐
7	The life story information that I collected about resident will be useful for staff in providing better care.	☐	☐	☐	☐	☐
8	I would recommend the life story program to other nursing home volunteers.	☐	☐	☐	☐	☐
9	I think it's feasible for volunteers to collect life stories in nursing homes across the state.	☐	☐	☐	☐	☐

SECTION D: SATISFACTION WITH THE VOLUNTEER EXPERIENCE

Please answer a few questions about your past volunteering experiences.

1	**Have you ever done any kind of volunteer work before?**	
	☐ YES (1)	☐ NO (SKIP TO QUESTION 4) (0)
2	**How long have you been a volunteer?_____years_____months**	
3	**Have you ever volunteered in a nursing home before?**	
	☐ YES (1)	☐ NO (0)

4	**Why did you decide to volunteer to participate in the LifeBio project? (PLEASE CHECK ALL THAT APPLY)**	
	☐1	A close relative of mine lives in a nursing home.
	☐1	I enjoy volunteering with older adults.
	☐1	I like volunteering in nursing homes.
	☐1	I feel sorry for nursing home residents.
	☐**1**	I like learning about other people's histories and backgrounds.
	☐1	I was already a volunteer in a nursing home that was selected for this study.
	☐1	I am familiar with creating life histories for nursing home residents and wanted to volunteer with a program that does this.
	☐1	OTHER (PLEASE SPECIFY):

Please read the following questions and select the response that reflects your views of your volunteer experience with the LifeBio program.

How satisfied were you with…		Very dissatisfied (1)	Dissatisfied (2)	Neither dissatisfied or satisfied (3)	Satisfied (4)	Very satisfied (5)
5	Your interactions with the nursing home residents?	☐	☐	☐	☐	☐
6	Your interactions with the nursing home staff?	☐	☐	☐	☐	☐
7	The nursing home environment (for example, cleanliness and smell)?	☐	☐	☐	☐	☐
8	The training you were provided to complete the project?	☐	☐	☐	☐	☐
9	The supplies you were provided to complete the project?	☐	☐	☐	☐	☐
10	Your experience overall with gathering life histories from nursing home residents?	☐	☐	☐	☐	☐

11	Would you recommend that your family or friend volunteer on a similar project, creating life histories for nursing home residents?	
	☐ **1** YES	☐ 0 NO

SECTION E: CONCLUSION

Is there anything else you would like us to know about your volunteering experience? Please describe in the box below.

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS SURVEY.

YOUR PARTICIPATION IN THIS PROJECT PROVIDES VALUABLE INFORMATION FOR IMPROVING THE LIVES OF NURSING HOME RESIDENTS.

PLEASE RETURN YOUR COMPLETED CONSENT FORM AND SURVEY TO BENJAMIN ROSE INSTITUTE ON AGING USING THE ENCLOSED POSTAGE-PAID ENVELOPE.

ONCE AGAIN, THANK YOU FOR YOUR TIME AND PARTICIPATION.

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Appendix C: Nursing Home Sampling Tables and Characteristics

Table C1: Nursing Home (NH) Sample Characteristics from Site Liaisons Based on NH Census, Minimum Data Set, and Recruitment Flyers

Nursing Home ID	Total Residents	Residents Enrolled in Medicaid	Medicaid, Long-Stay Residents	Medicaid, Long-Stay Residents Older Age 60 or Older	Residents With a BIMS of 8 or Higher	Residents Excluded – Non-English Speaking, Hospice, or Locked Unit	Total Eligible for Interview Based on Information From Site Liaisons	Residents Excluded Because of Non-Consenting Legal Guardians	Residents Who Declined Participation Via Flyer
NH1	83	69	66	66	31	9	22	0	2
NH2	160	119	115	88	52	28	24	0	5
NH3	81	51	49	49	31	1	30	1	4
NH4	49	35	32	17	17	1	16	0	3
NH5	156	142	114	88	61	11	50	11	22
NH6	82	62	61	52	36	13	23	1	3
NH7	163	115	115	115	53	2	51	2	22
NH8	119	72	69	68	44	0	44	1	26
NH9	141	126	126	67	38	22	16	3	1
NH10	130	86	86	82	30	1	29	1	1
NH11	108	94	94	85	51	3	48	1	1
NH12	147	79	79	68	45	9	36	1	18
NH13	111	73	70	68	61	2	59	0	28
NH14	70	69	69	61	37	4	33	4	14
NH15	142	120	120	98	90	31	59	9	15
NH16	75	53	53	44	30	1	29	2	9
Attrition		451	47	202	409	138		37	174
Total	1,817	1,365	1,318	1,116	707		569	532	358

Table C2: Characteristics of Nursing Homes (NH) Participating in LifeBio Project

Nursing Home ID	Total Residents	Medicaid Residents	Medicaid Utilization Percent	Overall Nursing Home Compare Quality Star Rating	Auspice	County of Operation
NH1	92	68	74%	4	For profit - Individual	Ashtabula
NH2	165	145	88%	4	For profit - Corporation	Ashtabula
NH3	84	58	69%	5	For profit - Individual	Ashtabula
NH4	61	33	53%	5	For profit - Corporation	Ashtabula
NH5	159	140	88%	3	For profit - Corporation	Cuyahoga
NH6	109	71	65%	3	For profit - Corporation	Cuyahoga
NH7	168	102	61%	3	Non profit - Church related	Cuyahoga
NH8	123	68	55%	3	Non profit - Church related	Cuyahoga
NH9	167	143	86%	2	For profit - Individual	Cuyahoga
NH10	146	107	73%	2	For profit - Partnership	Cuyahoga
NH11	115	78	68%	2	For profit - Corporation	Cuyahoga
NH12	142	80	56%	4	For profit - Corporation	Cuyahoga
NH13	100	65	65%	5	For profit - Corporation	Cuyahoga
NH14	72	70	97%	4	For profit - Corporation	Cuyahoga
NH15	165	137	83%	2	Non profit - Corporation	Cuyahoga
NH16	71	48	67%	1	For profit - Corporation	Cuyahoga
Total	1,939	1,413				
Average	121	88				
Median	119	77	69%	3		

Note. Data from the Ohio Governor's Office of Health Transformation and Medicare Nursing Home Compare, FY 2017.

Table C3: T1 Resident Interview Response Rates by Nursing Home (NH)

Nursing Home ID	Residents Who Opted to Speak with the Research Team	Residents Who Failed the BIMs at T1 Interview	Attrition – Transfers, Discharges, or Unable to Participate	Total Residents Eligible and Available	Refusals	Interviews Completed	Response Rate for Eligible and Available Residents
NH1	20	1	2	17	3	14	82%
NH2	19	0	3	16	5	11	69%
NH3	25	0	1	24	6	18	75%
NH4	13	1	2	10	1	9	90%
NH5	17	0	1	16	1	15	94%
NH6	19	0	0	19	3	16	84%
NH7	27	5	0	22	5	17	77%
NH8	17	0	2	15	3	12	80%
NH9	12	2	0	10	2	8	80%
NH10	27	3	1	23	7	16	70%
NH11	46	1	6	39	13	26	67%
NH12	17	0	0	17	2	15	88%
NH13	31	4	2	25	6	19	76%
NH14	15	1	0	14	4	10	71%
NH15	35	2	0	33	15	18	55%
NH16	18	0	1	17	3	14	82%
Attrition		20	21		79		
Total	358	338	317	317		238	75%

Table C4: T2 and T3 Resident Interview Response Rates by Nursing Home (NH)

	T2					T3				
Nursing Home ID	Total Residents Eligible and Available	Attrition – Transfers, Discharges, or Unable to Participate	Refusals	Interviews Completed	Response Rate for Eligible and Available Residents	Total Residents Eligible and Available	Attrition – Transfers, Discharges, or Unable to Participate	Refusals	Interviews Completed	Response Rate for Eligible and Available Residents
NH1	14	1	1	12	92%	12	0	0	12	100%
NH2	11	2	0	9	100%	9	0	0	9	100%
NH3	18	5	3	10	77%	10	0	0	10	100%
NH4	9	0	0	9	100%	9	0	0	9	100%
NH5	15	1	1	13	93%	13	0	0	13	100%
NH6	16	3	2	11	85%	11	0	0	11	100%
NH7	17	3	1	13	93%	13	2	0	11	100%
NH8	12	0	0	12	100%	12	2	0	10	100%
NH9	8	1	0	7	100%	7	0	0	7	100%
NH10	16	3	0	13	100%	13	3	0	10	100%
NH11	26	6	2	18	90%	18	4	0	14	100%
NH12	15	3	0	12	100%	12	0	1	11	91%
NH13	19	2	2	15	88%	15	2	0	13	100%
NH14	10	0	1	9	100%	9	1	1	7	88%
NH15	18	0	2	16	100%	16	0	0	16	100%
NH16	14	5	2	7	78%	7	0	0	7	100%
Attrition		35	17				14	2		
Total	238	203		186	92%	186	172		170	99%

Table C5: T1 and T2 Staff Surveys Received by Nursing Home (NH)

Nursing Home ID	T1 Staff Surveys Received	Staff Confirmed No Longer Employed at NH at T2	Staff Surveys Distributed at T2	Surveys Not Returned to BRIA	T2 Staff Surveys Received
NH1	30	0	31	16	15
NH2	9	0	9	3	6
NH3	7	0	7	4	3
NH4	4	0	3	0	3
NH5	11	2	9	4	5
NH6	13	2	11	8	3
NH7	16	2	14	4	10
NH8	12	0	12	3	9
NH9	7	0	7	4	3
NH10	37	9	28	22	6
NH11	18	1	17	10	7
NH12	5	0	5	1	4
NH13	10	0	10	2	8
NH14	1	0	1	0	1
NH15	15	0	15	9	6
NH16	3	0	3	0	3
Attrition		16		90	
Total	198		182		92

Table C6: T1 and T2 Surveys Received From Family Members of Participating Residents by Nursing Home (NH)

Nursing Home ID	T1 Family Surveys Received	T1 Family Surveys with a Participating Resident	Participating Family with Residents who Declined a Life Story	T2 Family Surveys Mailed	T2 Family Surveys Received
NH1	3	3	1	2	1
NH2	1	0	0	0	0
NH3	0	0	0	0	0
NH4	4	2	0	2	2
NH5	2	2	0	2	0
NH6	6	6	1	4	3
NH7	6	6	2	4	2
NH8	5	3	0	3	2
NH9	1	1	0	1	1
NH10	8	8	2	6	2
NH11	1	0	0	0	0
NH12	4	5	0	4	4
NH13	16	12	3	10	7
NH14	3	2	1	2	1
NH15	4	4	0	4	3
NH16	5	2	0	2	2
Attrition		13	10		16
Total	69	56	46	46	30

Introduction

One of the goals of the LifeBio Pilot Study was to assess the feasibility of using volunteers to sustain and expand the LifeBio program to other NFs in Ohio as a means of improving quality of care. The Universal Health Care Action Network of Ohio (UHCAN Ohio) was chosen to recruit, train, coordinate, and supervise volunteers to collect biographical data (life stories) with nursing home residents and family members for the LifeBio Pilot Study because of its history of communicating, networking, and partnering with a variety of stakeholders.

RECRUITMENT

Recruitment efforts for the LifeBio Pilot Study were focused on local colleges and universities and faith-based and community organizations in Ashtabula and Cuyahoga counties. Recruitment activities included email communications and the distribution of materials, developed by UHCAN Ohio, including recruitment flyers (see Resource 5) and a Frequently Asked Questions page (see Resource 6). In-person meetings were also set up with interested parties and presentations were given at community organizations and in classrooms. Nursing facility volunteers were also asked to volunteer for the project through nursing facility liaisons and additional recruitment efforts were made through non-profit organizations, local vocational high schools, local libraries, other volunteer sites, and personal contacts on the LifeBio Pilot Study project team. See Resource 7 for a full list of recruitment organizations.

Successes

Recruitment efforts were most successful at local community centers, particularly the Solon Senior Center and Cleveland Jewish Center with 10 and 12 volunteers, respectively, joining the volunteer project team from each organization. Three volunteers from the participating nursing facilities and one volunteer from a community health center also joined the project volunteer team. The Cleveland Jewish Community Center has a program called IMPACT! that drew in the most interest. This program is geared towards volunteers aged 50 and older who are interested in short-term volunteer assignments. Likewise, the Solon Senior Center offers enrichment activities and supportive services to adults 60 and older. This demographic of volunteers – adults with flexible schedules and ability to provide their own transportation to and from nursing facility sites – appeared to be the best fit for the needs of this project.

Challenges

Efforts to recruit volunteers at local colleges, universities, vocational high schools, and other non-profit organizations were not as successful in generating interest and retaining volunteers as the local community groups. College and university student recruitment faced challenges in aligning the project timeline with the academic calendar, and coordination of transportation posed a barrier for students. Inclement weather conditions in northeast Ohio during the winter months

dampened recruitment efforts as did the timing of the project activities with fall and winter holidays. Some older volunteers traveled south and were not available during the winter months. This contributed to low retention. Retention was also affected by administrative pauses in the project.

Screening Process

The NHs that participated in this project did not require their volunteers to receive screenings, so it was determined that volunteers recruited to participate from the community would not be screened beyond the screening performed by their organization (e.g., the Cleveland Jewish Federation).

TRAINING

Before volunteers began collecting and recording biographical data from nursing facility residents, they were provided with a three-hour training that included the purpose of the LifeBio Pilot Study, a review of the questions the volunteers would be asking nursing facility residents, role-play between volunteers to practice collecting biographical data, and a checklist for volunteers to review and take with them to the nursing facilities to ensure all aspects of the interviews were covered (e.g., wearing a name badge, taking a photo of the resident, conducting the QI interview, etc.). See Resource 2 for the volunteer training materials.

A total of 30 volunteers were trained at 11 training sessions. Trainings took place at the Solon Senior Center, Benjamin Rose Institute on Aging (2), Cleveland Jewish Federation (5), two participating nursing facilities, and the Ashtabula Public Library.

COLLECTING LIFE STORIES

UHCAN Ohio communicated with NH administrators and activities directors to establish dates and times for volunteers to meet with residents to collect life histories which were then shared with the volunteers. Volunteers provided or arranged for their own transportation to and from the NHs. Private spaces were the preferred location for life history information to be collected. When a resident's room was not available for the interview, a public space that allowed for some degree of privacy was chosen. Interviews with residents lasted approximately one hour in duration and included the collection of the resident's biographical information, using the About Me Journal (see Resource 1), and the LifeBio Quality Improvement Time 2 (T2) Survey (Appendix A, B8—B9). For the first 10 interviews, UHCAN Ohio mailed the life stories to LifeBio, Inc. and the surveys to BRIA in postage paid envelopes. After receiving feedback from volunteers, the process was changed to allow volunteers to write details from their notes into the About Me Journal after the interview and mail the books directly to LifeBio, Inc. in a postage-paid envelope. Volunteers were not provided with compensation for their time.

Use of LifeBio Staff and Volunteers

A total of 14 volunteers conducted at least one interview in 7 of the 16 participating NHs. Volunteers conducted a total of 30 interviews (16%) of the 186 total interviews completed as part of this study. Due to project delays and the lack of interest from community members to participate in the project, UHCAN Ohio was not able to recruit enough volunteers to conduct all of the interviews with the participating NH residents. An additional 27

total volunteers, interns, and employees from LifeBio, Inc. and BRIA were utilized to conduct the remaining 156 (84%) interviews.

BARRIERS AND RECOMMENDATIONS

After the completion of the biographical interviews, community volunteers were sent a survey that included questions covering demographics, experiences with the program, perceived usefulness of life stories, and satisfaction with their experience in the NHs. Volunteers were also asked for feedback in informal settings. The following is a list of recommendations for future projects based on observations during the project and feedback received from volunteers.

1. Contact all academic institutions far in advance of the project to determine how the project timeline can be aligned with the academic calendar. Consider working with school volunteer clubs and organizations as club activities typically take place throughout the entire academic year.

2. Pursue an option for the instructor to offer academic credit for volunteering. Consider working with school volunteer clubs and organizations that have an interest in volunteer work.

3. Work with an established academic club or organization or the school to arrange for transportation options well in advance of the project start date.

4. Include the notification of residents and family members on when volunteers are scheduled to collect life stories in the staff training, and remind the NH contact who schedules the interviews to distribute the information to residents and family members. Provide reminder cards to the NH to give to residents and family members with the scheduled interview dates and times.

5. When possible, avoid conducting interviews during the winter months. If this cannot be avoided, try to arrange carpools or other transportation. If interviews will take place close to religious holidays, work with organizations to promote the volunteer opportunity with other volunteer opportunities taking place at that time (e.g., feeding the homeless at Thanksgiving, caroling, etc.). Recruit student volunteers who may be on a school break or home from college during the holiday season.

6. Set up consecutive 6-8 week time periods for volunteers to choose from to commit to the project to accommodate for volunteers who do not want to make a long-term commitment to the project. Establish a communication strategy to promptly notify volunteers of interview dates and times.

7. Communicate with NHs and volunteers when project delays may take place and the process for reengaging them once work can begin. When possible, continue to provide updates to all parties on when the project is expected to resume and express excitement for their continued participation.

8. Update trainings to include how to probe residents for answers to questions, cultural diversity that addresses aging, culture and gender bias, and other factors that might impact the interaction of volunteers with the participants.

RESIDENT AND INTERVIEWER OBSERVATIONS AND FEEDBACK

When LifeBio, Inc. presented residents with their booklets and snapshots, residents appeared to be most interested in the one-page Snapshot summaries of their lives, sometimes even more so than the more detailed and longer Booklet. The Snapshots were designed to be visually appealing and easy to read. They included information that could be used to start a conversation or help the reader understand the residents' interests and preferences.

On several occasions, residents were observed asking their direct care staff to read their Snapshots, **"Look – There's my story!"** Thus, the Snapshot provided a tool for residents to advocate for their own person-centered care if they could encourage staff to read the Snapshot and get to know more about the resident, their history, and preferences. Simple needs were communicated, such as:

- "I want to plant a pumpkin." (There was a community garden across the street.)
- "I want to cook again."
- "I want to go to softball/baseball game." (There was a baseball field next door.)
- "I need a pencil and paper to keep a journal."
- "I'd like to learn to play the guitar."

FAMILY REACTIONS

Attempts were made to connect with family members of all participating residents. These

"Both family members thought the books were beautiful (after they were interviewed by phone to share their mothers' stories). The pictures they sent (via email to LifeBio, Inc.) were also presented very nicely. And, they said now their mothers' stories can be shared not only with their families – but also with the staff. They both said they would recommend LifeBio to anyone that would like to preserve the life stories of their loved ones."

- Participating NH Activities Staff Directory

interviews were conducted over the phone by LifeBio, Inc.'s staff members. Many of these connections were unsuccessful. In many cases, residents had very little involvement from their family members. In some cases, a guardians expressed they did not have enough information to tell LifeBio about the resident; the guardian could make legal decisions for the resident, but the guardian did not know a great deal of personal life history information.

Overall, LifeBio, Inc. received positive anecdotal feedback from NH staff and family members.

In another instance, LifeBio, Inc. received information that a resident had passed away shortly after receiving his life story booklet and summary. The family expressed gratitude for the resident's participation in the project and the book was shared during this resident's wake.

STAFF REACTIONS

There were opportunities for staff to interact with the resident and the interviewer during the interviews. In some instances, staff members did not interact at all when interviews were taking place. In other cases, staff members participated in the life story interviewing process. Interviewers observed that their participation improved the quality of the interview.

There were some sites where both activity directors and other staff members were glad LifeBio, Inc. was involved, but they were not interested in participating in final Booklet or Snapshot presentations. On the other hand, at another site the activity director relished in the opportunity to present the Booklets and Snapshots to her residents and involved the direct care staff workers to read them as well. The staff members in many locations reported that they learned more about their residents than they had known before and were identifying more opportunities to share stories with other staff. One NH adopted the practice of sharing one Snapshot and Booklet each week during staff meetings.

In multiple instances, staff expressed clear benefits from receiving knowledge about the whole person (participating residents) from

the Snapshots and Action Plans. The closeness between residents and staff could be clearly felt at many of the NHs. Staff members learned something significant about residents at each presentation. In one case, they learned a resident was still married and her husband was still alive! They marveled at her wedding photos. In other cases, they learned they had similarities, such as attending the same school and liking the same sport. Staff reacted to younger photos of residents on the Snapshots. They would comment, **"That was you?!"**

One of the best presentations occurred when a resident's brother was visiting. The Snapshot was read aloud by the activity director with the CNA listening as well. The brother expressed that he enjoyed it as much as the resident; it reminded both brothers of past experiences. (One of the main powers of reminiscence and life review is taking people "back in time" to a happier place in his or her mind). Interaction between staff and the brothers was heartfelt: **"Remember when…"** and laughter ensued.

STANDOUT INTERACTIONS BETWEEN RESIDENTS AND INTERVIEWERS:

One interviewer walked into a darkened room at 3 p.m., in the afternoon with a 65-year-old man facing the wall. Before arriving at the NH, LifeBio, Inc. was informed that he would probably not want to participate. Still, LifeBio, Inc. attempted to ask in person if he would like to proceed with the interview. After in a few minutes, he met the interviewer in the hallway and walked to an activity room where the interview occurred. *A resident who was initially reluctant to speak became enthusiastic to share his life story with the interviewer.* He described growing up in a neighborhood like "A Christmas Story" and shared about his two sons and his love of 1,000-piece puzzles and much, much more. *Immediately after the interview, his mood appeared to be more positive and he showed interest in interacting with other residents rather than returning to his room.*

A LifeBio, Inc. interviewer entered a room and introduced herself. She shared about the LifeBio Pilot Study and the gentleman said to her, "Yes, yes! I know who you are. I hoped you hadn't forgotten about me!" He then pointed to his bulletin board, where he had pinned up the flyer that the NH staff had given to him at the time of recruitment (months earlier). *Next to his bed on his bedside table, he had laid out his photo album, which he wanted her to see. He went through each photo and shared his stories.*

Even more significant, though, was the fact that this gentleman did NOT have a good childhood. As a matter of fact, his father had been quite abusive. As interviewers are trained to do, the interviewer gently asked the gentleman if he wanted these facts included in his book. The gentleman was adamant when he assured her that, yes, he wanted to tell his story just the way it happened. *It was evident to the interviewer that the resident was able to achieve some sense of peace in the telling, and he was proud of his ability to overcome adversity in his life.*

There was a resident who was homeless before coming to the community. *He had been robbed, beaten, and left injured in the parking lot of a bar.* When he was brought to the NH, he had many psychological issues. After the interviewer was done with his life story, she invited some other LifeBio, Inc. team members in to meet the gentleman, to say hello, and to thank him for sharing his story. The next day when the team returned to conclude interviews at this site, the head nurse pulled the interviewer to the side. The nurse said, "I just want you to know what your visit meant to 'John.' After you left, he told me that you made him feel like a movie star." He said, "They are going to make a book about me, and I want everyone to read it." He ended with this exact quote, "I used to feel like an oddity – but they made me feel like I am an exception!"

VOLUNTEERS / LIFEBIO, INC. INTERNS

Participation in this pilot studyhad a profound impact on the LifeBio, Inc. volunteer interns, and staff who were involved. Below are highlights of the feedback received by LifeBio,

Inc. that were echoed by many of the individuals who collected life stories.

"Elsie was blind, but she kept telling me how handsome I was! She liked the sound of my voice and the sound of laugh (glowing from ear to ear). It was truly inspirational. I came in contact with a person whose story is closer to the end (of life), and I am closer to the beginning. It was something that not a lot of people get to experience."

- Evan (College Student Intern)

"I had a wonderful time interviewing this sweet lady. She just so loves telling her story. Just about how wonderful her childhood was. She would give her lunch to a boy who had no lunch. She grew up in the Great Depression. She cared about other people and her church. It made me think about what I am thankful for in my life. It was just a cool experience and I would definitely do it again."

– Rachel (College Student Intern)

"When I got here, I was introduced to a man who was very quiet with head to the ground. The nurses said he would not be up to speaking with me. I tried anyway, and we had a good conversation. We talked for 45 minutes or an hour. He was an Army veteran. He told me about his biggest regrets; he lost a real estate company. He told me about his wife and sons. Overall, we had a good

conversation and that all happened from a man who seemingly didn't want to speak to anyone."

– Nora (College Student Intern)

"I talked to a wonderful woman today. She is also a musician. As a music student, it was really cool to build that rapport very early on. We both got to explain what music meant to both of us. It was really cool that music fills that gap between generations. She got to share her life mottos. It was really cool to hear about her music career and how it changed her life. I'm really glad I got to be part of this and build that relationship."

– Sara Jane (College Student Intern)

"Today was so wonderful, and I think everyone of any age should speak with someone of another generation. The reason she never married was because no one ever amounted to someone as good as her father was. We should think about that. The art of getting to know someone is getting lost. We should definitely make that part of our lives. If we start doing this now, then by the time we are this age there will people that care about us too. And the cycle will just keep going on."

– Micayla (College Student Intern)

"I had someone who was fairly challenging (he had great difficulty talking—but he was trying), I learned from this experience. I learned how to be patient. I got to know them through their life stories. It was really interesting."

– Brienna (College Student Intern)

LESSONS LEARNED & THE FUTURE

1. Printing of the Snapshots (digitally and/or in print form) will continue and Action Plans will be provided for behind-the-scenes use by staff. Printing the Booklet could be optional with just the detailed version stored online only.

2. The Action Plans are evolving to be even more useful to care staff to view and use; they now have more space for "care info," suggestions for activity and interests, life story background information.

3. The About Me Journal was effective in gathering the information LifeBio, Inc. needed to generate the Booklets and Snapshots, but LifeBio, Inc. is adapting the About Me Journal to streamline the creation of detailed Snapshots and highly useful Action Plan.

4. Individuals were upset with name misspellings and typographical errors which occurred due to human error in the interview process. Recording data by hand can interrupt the narrative flow, but using digital recording devices poses significant transcription time. The following changes are suggested:

    a. Improve the training of interviewers to double check the spelling of key information;

b. Update the LifeBio, Inc. editing process to ensure the reduction of errors to properly preserve dignity and legacy;

c. Consider the use of online audio recording methods and automatic transcription services;

d. Provide an opportunity for staff and family members to review books and make edits and updates to Booklets and Snapshots before delivery (the About Me Journal is now accessible online for future projects, if reliable WiFi is available);

e. Place the information that is currently at the back of the Booklet – a page describing how residents and family members can access www.lifebio.com or contact LifeBio, Inc. by phone or email to request any corrections to their Life Story Book – in a more predominant location (e.g. the front of the Life Story Book or on a separate, distinct sheet).

5. The online version of LifeBio will be more and more attractive to the residents and their families, as seniors and their family members become more technology savvy. This will be the place where more detailed information can be stored and recorded. Tablets could be provided by LifeBio, Inc. for the entry of biographical data for residents, family, staff, and volunteers to complete.

6. The Quality Improvement phase was limited by the project's tight timeline. There was limited time to allow residents not eligible for the research portion of the project to participate. Onsite visits would have beenscheduled instead of phone interviews in order to maximize resident participation in this phase of the study, but the timeline would have had to be extended to make this happen. After conducting these interviews over the phone, it was learned that there are too many barriers to interviewing NH residents over the phone, so this approach will not be used in the future, if possible.

7. There were fewer participants in the QI portion of this study than LifeBio, Inc. was hoping. It will be important to determine what would make the program more engaging and attractive to residents and what might be more attractive to individuals in a Medicaid population.

8. During this project, there were some uncomfortable and emotional reactions with residents. LifeBio, Inc. will examine and improve trainings to address these concerns in the future. Interviewers will need to be prepared to hear about trauma, and LifeBio, Inc. will need to be aware that some residents have physical or mental limitations (cognitive challenges, sight, hearing, mobility, etc.) that may impact the interview. LifeBio, Inc. has many good examples from this project to share with future staff, interns, or volunteers to help in preparing them for the unexpected situations that may arise.

9. LifeBio, Inc. has identified several opportunities to improve the staff training. These include:

a. Migrating the training to an online platform to make it easier for staff in all shifts to participate and know how and why to use the person's snapshot and booklet in their work.

b. Further encouraging staff participation, interviewers may consider inviting staff to participate in the interview process, even if it is just for a few of the questions.

c. Adding training on how to use the materials after the end of the program, such as how to use the Booklet, Action Plan, and Snapshot to engage the resident while providing care.

10. Some volunteers faced challenges during the interview process. In one instance, a resident repeatedly asked inappropriate questions of the interviewer. The interviewer was trained and redirected the resident with different questions in a respectful way. Another interviewer was reminded of a family member during her interview, which made the interview difficult. It is important to ensure that volunteers understand it is okay to take a break, and that they have appropriate training for the situations.

11. Because the LifeBio "experience" had an immediate impact on residents – increased social engagement starting with the interview to receiving their finished Booklet and Snapshot – LifeBio, Inc. will look for ways to ensure staff members are reading the Snapshots out loud during the presentation and asking residents where they would like them to be displayed in their rooms. LifeBio, Inc. will also discuss and determine where the snapshots will be hung during initial meetings with NH administrators.

12. LifeBio, Inc. saw success in using paid interns and unpaid volunteers for the conducting of interviews. For timing and coordination of resources, it would make sense for LifeBio, Inc. to be involved more closely in this aspect of the project. LifeBio, Inc. would like to take a more active role in reaching out to organizations that can assist with volunteers. One or more college interns or LifeBio, Inc. staff members could assist in monitoring the sites, training and communicating with volunteers, and assisting with interviews.

13. LifeBio, Inc. has learned that sometimes visits point out simple needs and desires that could easily be turned into engagement for residents. LifeBio, Inc. is considering several ways of changing how they implement their program to improve engagement in the future, such as developing a program specifically for Alzheimer's and Dementia residents; how to use completed Booklets as a guide for conversation and engagement; and possibly developing personalized Activity Units for LifeBio, Inc. subscribers. Additionally, LifeBio, Inc. is an advocate for those that who are sharing their lives; when simple requests can be fulfilled, LifeBio, Inc. will help make sure these needs are addressed appropriately. It is important to LifeBio, Inc. for future volunteers, employees, interns and others to understand this role as well.

ABOUT ME

This Booklet is About

_____

_____

_____

This About Me Journal is about:

Name _____

Name I Prefer to Be Called _____

Email Address _____

Daytime Phone Number _____

Address _____

City _____ *State* _____ *Zip* _____

❍ I am completing the About Me Journal on my own.

❍ This About Me Journal was completed with assistance from:

Name _____

Email Address _____

Daytime Phone Number _____

Are you a... *(select one)*

❍ Relative *(how are you related?)* _____

❍ Volunteer ❍ Staff Member ❍ Friend

ABOUT ME JOURNAL

By Beth Sanders

Published by LifeBio, Inc.

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Note: The information from the About Me Journal can be transferred to the web by going to www.lifebio.com. Enter your email, password, and organization code to begin. Call 1-866-LIFEBIO or 937-303-4576 for assistance.

Please direct any comments or questions regarding this book to LifeBio by using the contact information below:

LifeBio, Inc.
232 N. Main St., Suite 2J
Marysville, OH 43040
866-LIFEBIO

For more information, visit www.LifeBio.com.

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R2

When and where were you born? Where have you lived most recently?

Describe your childhood home/hometown.

Pictures of childhood.

Pictures of childhood home or hometown.

Pictures of a recent home.

R3

Share about your family and other important people in your life.

Include people such your parents, grandparents, siblings, spouse, children, grandchildren, best friends (now or from the past!), etc. Don't forget to include names if possible (spelled correctly please).

Pictures of parents, grandparents, aunts, uncles.

Pictures of spouse, children, grandchildren, good friends, etc.

R4

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Photos & Memorabilia

R5

Where did you go to school?

Share about elementary, middle, high school, college, trade school, etc.
Do you remember sports, dances, or other events from your school days?

Pictures of elementary school, high school or other school buildings.

Pictures of friends from school days.

Pictures of high school or college mascot, logo, etc.

R6

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Describe the work you have done in your life.

What was your first job? Describe the jobs you had (around the house, paid work, or volunteering). What was your favorite/least favorite job?

Pictures of being on the job.

Pictures of working inside or outside the home.

R7

Who do you admire the most? What did this person teach you?

This could be a parent, a famous person, a mentor, a teacher, a person from history, etc.

Pictures of someone admired.

R8

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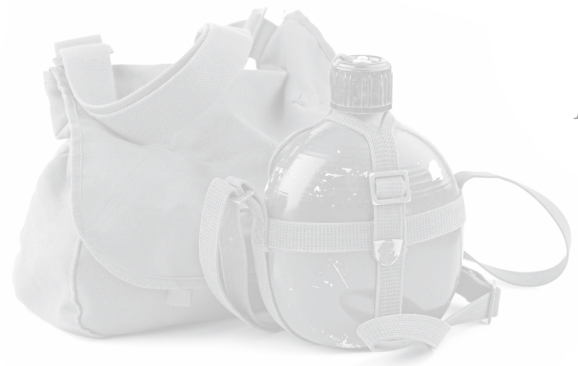
Describe historical events or life events that had an impact on you.

Where were you when these events happened?
In what way did this event impact you/your family?



Pictures of an event in history that had an impact.

Pictures of family events or other life events that matter.

R9

What are your favorite celebrations and holidays?
How do you like to celebrate?

Do you get together with family or friends?
Describe a memory of a favorite celebration or family tradition.

Pictures of celebrations and holidays.

Family photos of birthdays, anniversaries, holiday celebrations.

R10

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Which types of entertainment do you enjoy? What are some favorite…

TV Shows

_____

_____

Radio Stations

_____

_____

Movies

_____

_____

Plays/Theater

(*Were you ever involved in any plays or musicals?)*

_____

_____

Music

(*Do you have a favorite song? Do you have a favorite type of music or band such as rock, blues, country, jazz, classical, etc.? What do you like to sing? What instruments do you play?)*

_____

_____

Share a picture of a favorite TV show, movie, or play.

Share a picture of a favorite musician or band.

Make a list of favorite songs or hymns.

R11

What are your favorite hobbies, interests, places you like to go, and things you like to do?

_____

_____

Here are some great ideas below! If there is time provide more details. *X the boxes below*

Things to Do	Questions	Answers	Enjoy Now	Enjoyed in Past	Like to Try Now!
Animals/Zoo Visits	What are your favorite animals? Do you like dogs, cats, or other animals?				
Arts & Crafts	What are your favorite arts and crafts?				
Biography/Reminiscing	Do you enjoy telling stories of your past?				
Bird Watching	Where do you like to go? Favorite type to watch?				
Boating/Canoeing	What's your favorite spot to go boating or canoeing?				
Books/Reading	Do you like romances, biographies, or other types? Favorite author?				
Business/Financial/Stock Market	What companies interest you?				
Cars/Car Shows, Trucks, Motorcycles	What types of cars do you like? Trucks? Motorcycles?				
Classes	What are classes you would like to take?				
Clubs/Groups of Friends	When and where do you meet?				
Collecting	What do you collect?				
Cooking/Baking	What's your specialty?				
Crossword Puzzles/Trivia	What kinds of word/number games do you like?				
Dancing	What type of dancing is your favorite?				
Entertaining/Party Planning	Do you enjoy parties? Do you like to help plan parties?				
Exercise	What's your favorite kind of exercise? How often do you exercise?				

R12

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What are your favorite hobbies, interests, places you like to go, and things you like to do?

_____

_____

Here are some great ideas below! If there is time provide more details. *X the boxes below*

Things to Do	Questions	Answers	Enjoy Now	Enjoyed in Past	Like to Try Now!
Farming/Auctions	What do you like to see? What do you like to buy?				
Fishing	Where do you like to fish? What kinds of fish do you like to catch?				
Games/Cards	Do you like to play BINGO? Favorite board games? Video games? Favorite card games?				
Gardening	What do you like to grow? Flowers, vegetables, fruits?				
Genealogy	Have you researched your family tree?				
History	What interests you about history? What time period interests you?				
Jewelry Making/Beading	What do you like to make?				
Knitting/Crocheting	What do you like to make?				
Model Building	Do you like certain models---trains, planes, rockets, cars?				
Museums	Favorites? Art, History, Science?				
Nature Walking/Hiking	Where do you like to go? Favorite park or trail?				
News of the Day	Favorite newspaper or news program?				
Painting/Drawing	Charcoal, Pencil, Oil, Watercolors, Other?				
Photography/Film	What do you like to photograph or film?				
Pottery	What do you like to make?				
Puzzles	100 pieces? 500 pieces? 1000+ pieces?				

R13

What are your favorite hobbies, interests, places you like to go, and things you like to do?

_____

_____

Here are some great ideas below! If there is time provide more details. *X the boxes below*

Things to Do	Questions	Answers	Enjoy Now	Enjoyed in Past	Like to Try Now!
Quilting	Who taught you how to quilt? Do you quilt by hand or use a machine?				
Remote Control Cars/Helicopters	What got you interested in this hobby?				
Scrapbooking/ Photo Albums	What do you like to scrapbook about?				
Sewing/ Embroidery	What do you like to sew? Have you ever sewn clothes for yourself or your children?				
Shopping	Where are your favorite places to shop? What do you like to buy?				
Spiritual/ Religious Practices	Do you like to attend worship? What denomination or religion do you consider yourself to be?				
Sports – Playing	What do you like to play?				
Sports – Watching	What teams are your favorites to watch?				
Study of Scripture/Bible Study	Do you read or study scriptures or other religious texts? What specifically do you like to study?				
Technology/ Computers	What would you like to learn? Do you have your own computer?				
Travel/Local Trips	Where do you like to go? Do you like to watch travel videos?				
Volunteering	Where do you like to volunteer? Would you like to volunteer to help others here?				
Woodworking	What do you like to make?				
Writing/ Journaling	What do you like to write? Have you been published?				
Other					

R14

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What are some of your preferences?

Do you like to go outside? If so, what do you like to do? _____

_____

What is your favorite weather/favorite season? _____

_____

What do you like to do to pamper yourself? Hair, spa, clothes, outings, etc. _____

_____

What helps you feel better if you're upset? _____

_____

Do you consider yourself a morning person or do you like to stay up late? _____

_____

What do you like to eat or drink for breakfast, lunch, dinner, and snacks?

Breakfast _____

Lunch _____

Dinner _____

Snacks _____

What are things you DON'T like to eat or drink for breakfast, lunch, dinner, or snacks?

Breakfast _____

Lunch _____

Dinner _____

Snacks _____

R15

What do you consider to be your greatest accomplishment?

Show a picture of one or more accomplishments.

R16

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What are some of your dreams, plans, and goals?
Is there something you've always wanted to do that you've never done?

Share some pictures of dreams, plans, and goals.

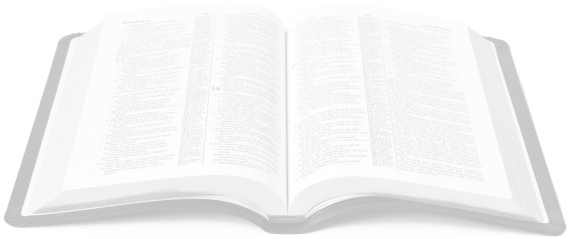
Share ideas of some things to do in the future.

R17

What are some important scriptures, sayings, or poems that you like?
Please share some advice to future generations.

Pictures or copies of a favorite scripture, saying, or poem.

Use a meaningful picture to show feelings of love and care.



R18

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Photos & Memorabilia

R19

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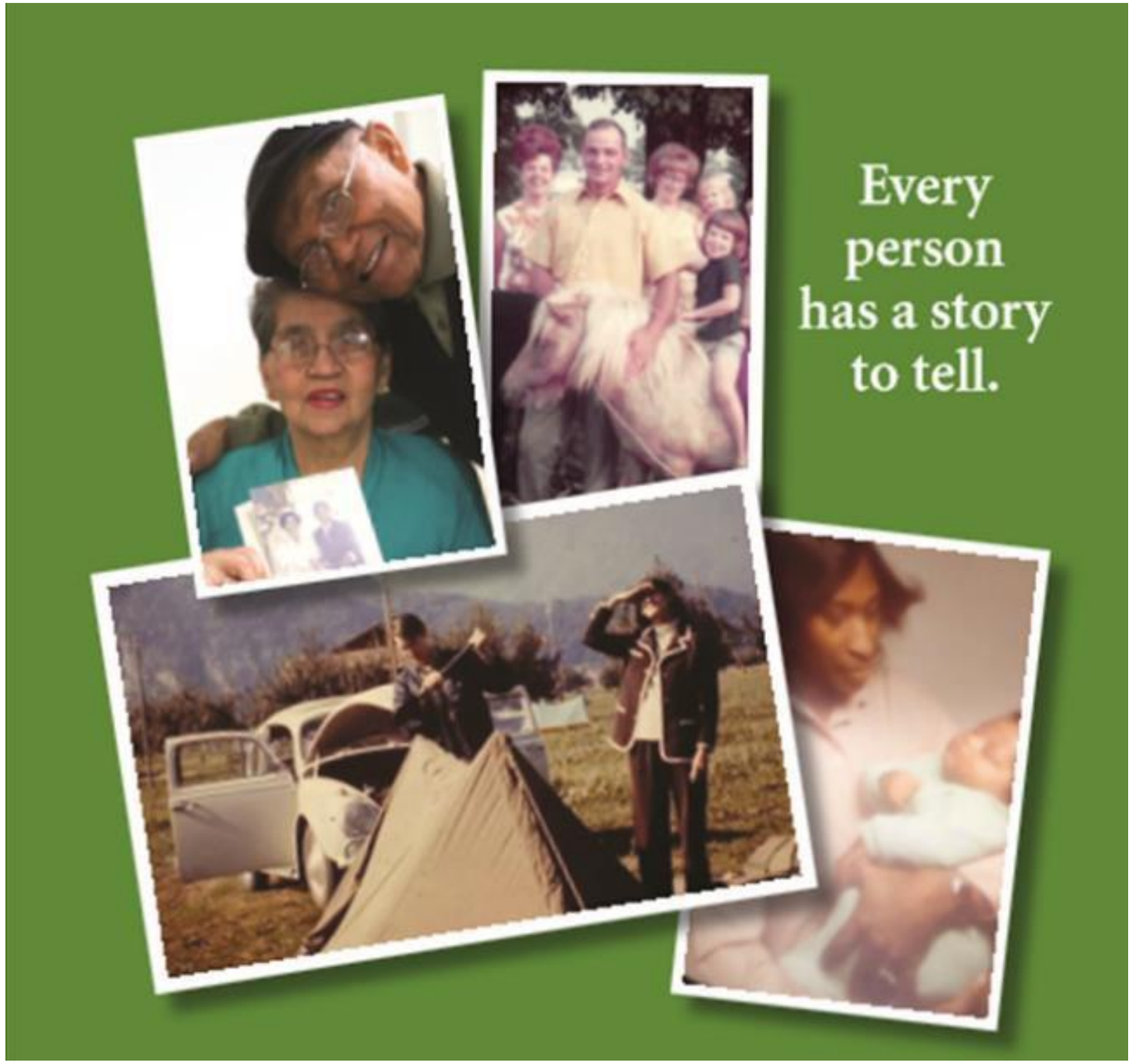
Thank you for agreeing to take part in this project.

The LifeBio Project will help capture the life stories of nursing home residents to support your commitment to <u>person-centered care</u>.

This pilot project is funded by the Ohio Department of Medicaid (ODM) and will be conducted by:

- **LifeBio**
- **Benjamin Rose Institute on Aging (BRIA)**
- **Ohio Colleges of Medicine Government Resource Center (GRC) at The Ohio State University**
- **Universal Health Care Action Network (UHCAN)**

What is the LifeBio Project?



Residents, staff, and family members will have the chance to share life stories, meaningful events, accomplishments, photos, and more.

Our Goals

- Capture life story information that will help staff (YOU!) know residents more deeply
- Improve residents' feelings of well-being and happiness (reduce drug usage if possible)
- Improve family satisfaction
- Build new connections with volunteers, staff, and family

Why is Life Story Work Useful?

- Knowing the life story can help staff members have greater feelings of empathy for nursing home residents.
- Talking about the person's life story may help calm or redirect a person with dementia.
- Ideas for personalizing activities and interests can result from knowing more about the person's life story.
- Residents can experience feelings of happiness and satisfaction with life as they have an opportunity to reminisce and use life review.

Person-Centered Care & Resident Rights

Centers for Medicare and Medicaid (CMS) regulations require person-centered care (483.5) to help residents make their own choices. The resident rights (483.10, F550) state the nursing home is required by CMS to treat residents with respect and dignity, maintain or enhance quality of life, and recognize individuality.

Comprehensive Person-Centered Care Planning – 483.21 (F272/F636 – F279/F656):

Know the resident's….

1. strengths

2. goals

3. life history

4. preferences

Attain or maintain the "resident's **highest practicable physical, mental, and psychosocial well-being**."

F279 cited 11,230 times in past 3 years nationally

Source: Squared Business Solutions

#5 most cited

R26

Activities - 483.24 (F248 / Revised F679)

An ongoing resident centered activities program that incorporates the resident's **interests, hobbies and cultural preferences** which is integral to maintaining and/or improving a resident's **physical, mental, and psychosocial well-being and independence**. To create opportunities for each resident to have a meaningful life by supporting his/her domains of wellness (security, autonomy, growth, connectedness, identity, joy and meaning).

F248 cited 2,379 times in past 3 years nationally

Source: Squared Business Solutions

#36 most cited

R27

DEMENTIA

Behavioral Health Services – 483.40/483.24 (F248/Revised F679)

The Centers for Medicare & Medicaid Services in the Behavioral Health Services regulation (483.40) says, the facility must assure "A resident who displays or is diagnosed with dementia, receives the appropriate treatment and services to attain or maintain his or her **highest practicable physical, mental, and psychosocial well-being."**

Activities must be **individualized and customized based on the resident's previous lifestyle (occupation, family, hobbies), preferences and comforts.**

R28

How does the LifeBio Project Work?

- The *About Me Journal*, developed by LifeBio, will be used by volunteers to interview residents enrolled in Medicaid.

- LifeBio will assist staff and volunteers in the finishing of these materials for each participant:

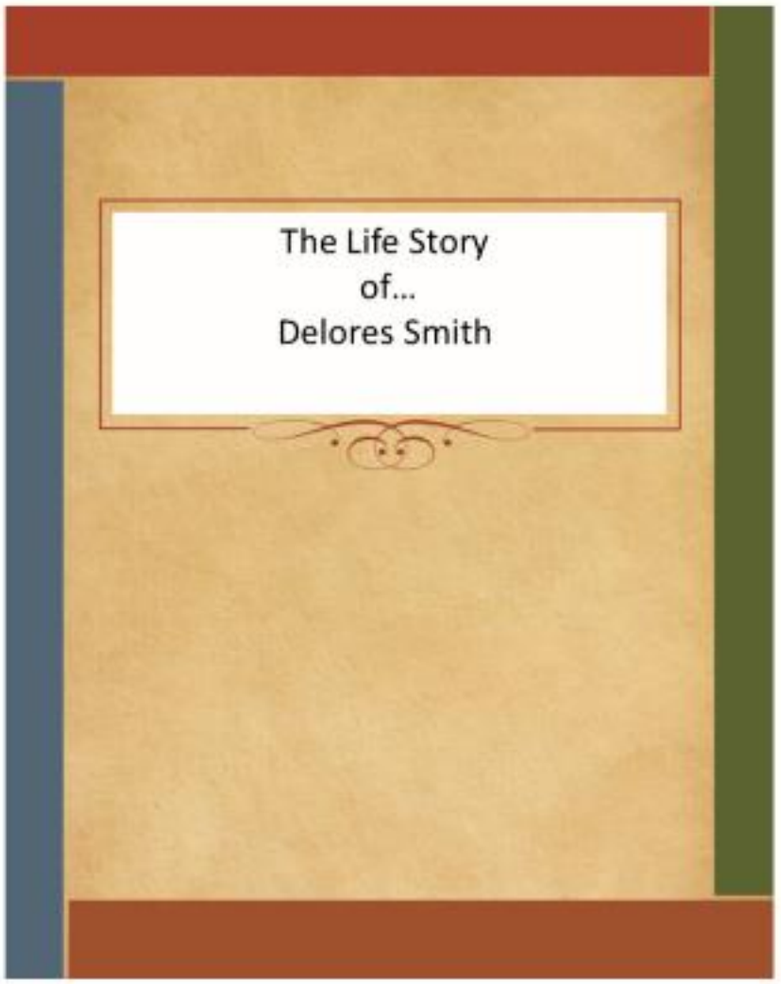
- The Life Story Booklet will be sent to you. Give this to the resident and family. This is enjoyable for them to see!

- A life summary, called the Life Story Snapshot (1-pager), will be printed and sent to you to read, use, and DISPLAY.

- A LifeBio Action Plan will be printed and sent to you to provide great ideas on things to talk about and things to do. Insert this in the care plan.

What LifeBio Delivers

Within 2-3 weeks, LifeBio will deliver these three things:



Delores

Delores was born in Luther, Michigan. Her father was a farmer and her mother was a school cook. Delores graduated from Luther High School and then attended Michigan State to become a **teacher**. Later, she earned her Master's degree at Capital University. Delores was a passionate teacher and never regretted her decision to pursue a career in education.

Delores and her husband, **Curt**, settled in Westerville, Ohio, and she taught for 30 years in Columbus Public Schools (4th Grade). She loved to travel and visited the **Galapagos Islands** once!

Delores appreciates family gatherings with her brother and sister, her adult **sons** and their wives (Jeff and Beth, Steve and Robin), and her teenage grandchildren, Melissa and David.

Delores loves nature and outdoor experiences such as flower gardening and birdwatching (especially **hummingbirds**!). Delores likes to keep up to date with the news, and she enjoys listening to **music**, going on trips, or attending Bible studies. Painting is another favorite hobby, as is **shopping**! Her favorite store is Macy's; she loves to shop for new clothes. Delores enjoys dining out, drinking tea, and eating chocolate!

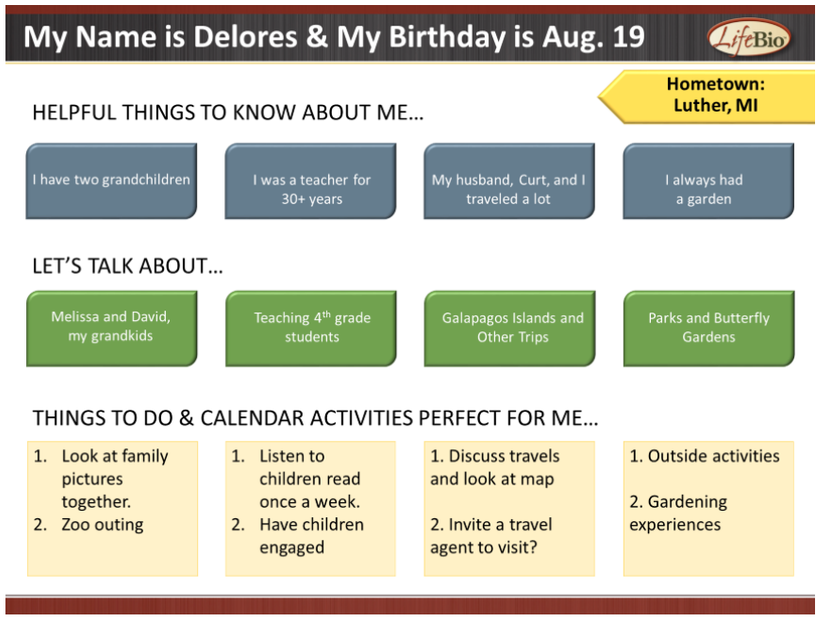
If there is one wish Delores has, it would be to teach again. She considers teaching her greatest accomplishment.

"Every day is a new adventure!"

Let's Talk About...

My family
Teaching
Shopping
Bird-watching

#1 Teacher



My Name is Delores & My Birthday is Aug. 19

Hometown: Luther, MI

HELPFUL THINGS TO KNOW ABOUT ME...

- I have two grandchildren
- I was a teacher for 30+ years
- My husband, Curt, and I traveled a lot
- I always had a garden

LET'S TALK ABOUT...

- Melissa and David, my grandkids
- Teaching 4th grade students
- Galapagos Islands and Other Trips
- Parks and Butterfly Gardens

THINGS TO DO & CALENDAR ACTIVITIES PERFECT FOR ME...

1. Look at family pictures together.
2. Zoo outing

1. Listen to children read once a week.
2. Have children engaged

1. Discuss travels and look at map
2. Invite a travel agent to visit?

1. Outside activities
2. Gardening experiences

Overview of the Forms and Contents

SCAN to: connect@lifebio.com

MAIL and TRACK to:

LifeBio

232 N. Main Street, Suite 2J, Marysville, OH 43040

R31

It all starts with a Question!

This is information on my background...
(when and where I was born, where I lived most recently)

I was born in Luther, Michigan. We were farmers. Now, I live in Delaware, Ohio. I lived in Westerville, Ohio and my kids went to Westerville schools.

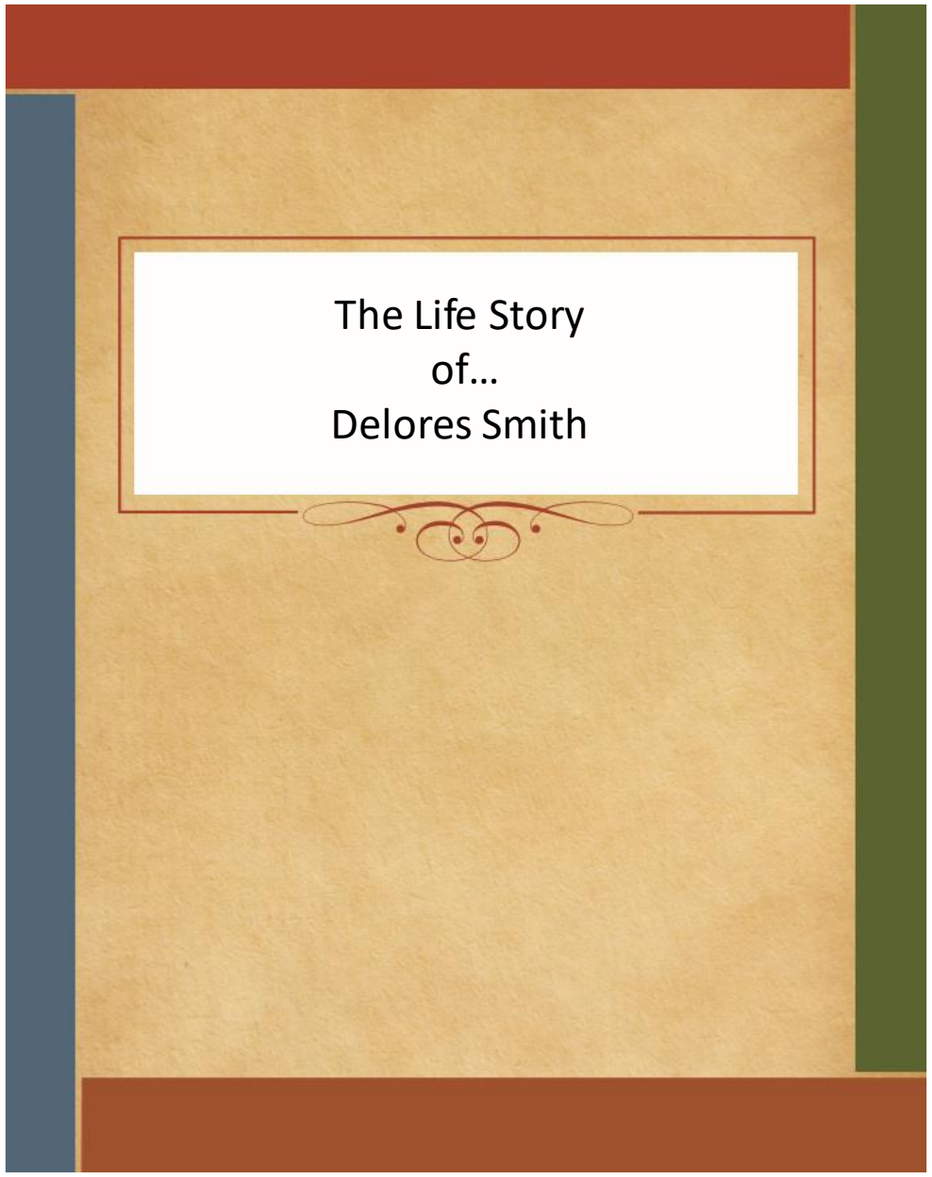
This is information on the work I have done in my life...

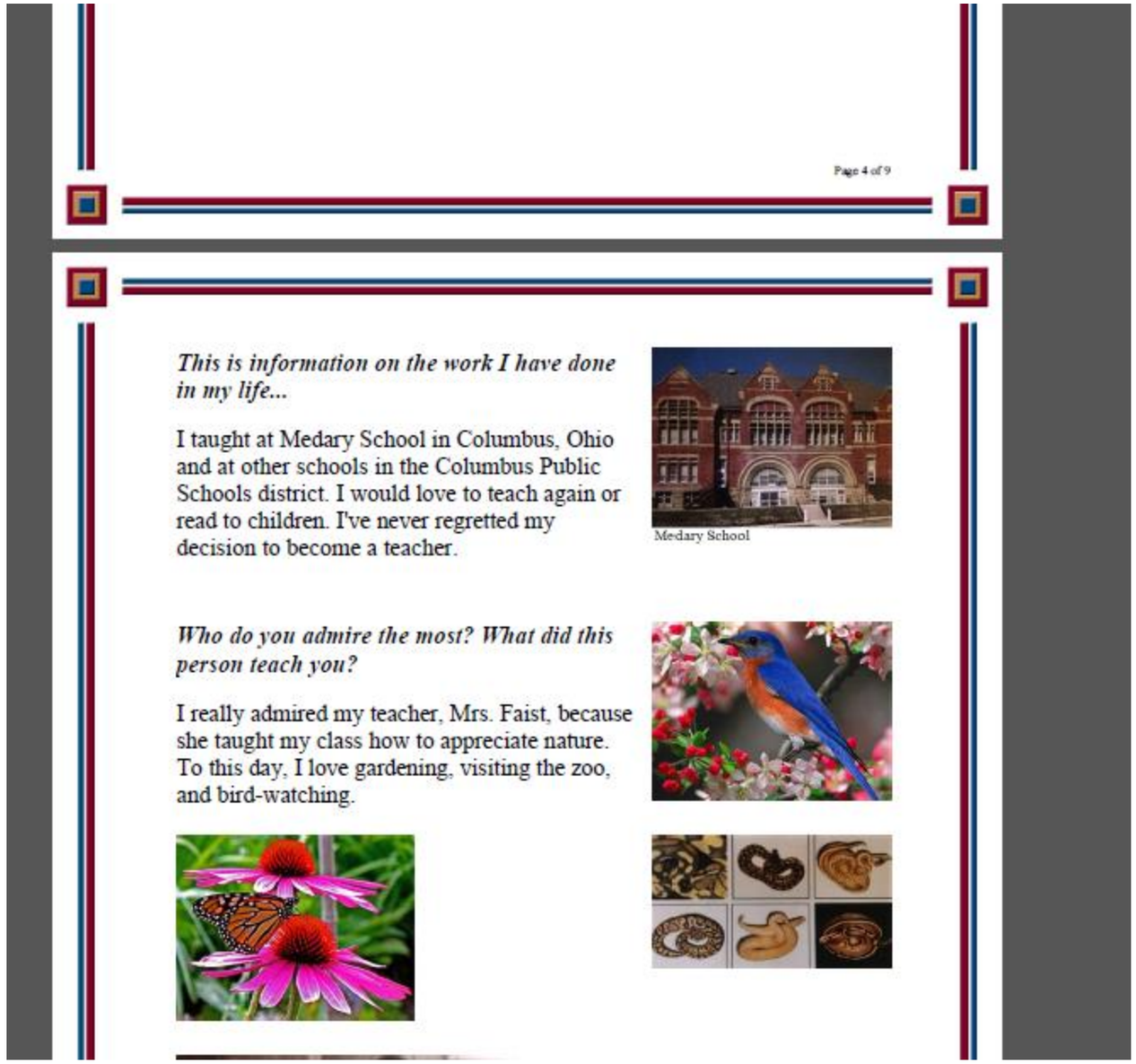
I began teaching at Medary School in Columbus, Ohio shortly after graduating from college. I would love to teach again or read to children. I never regretted my decision to become a teacher.

I have these hobbies, interests, places I like to go, and things I like to do...

- My grandchildren and I would always go to to Columbus Zoo. We like the polar bear exhibit. I also like the reptiles room.
- I like to do any kinds of crafts
- I go to Sharon Woods to bird watch.

LifeBio generates a Life Story Booklet





Page 4 of 9

This is information on the work I have done in my life…

I taught at Medary School in Columbus, Ohio and at other schools in the Columbus Public Schools district. I would love to teach again or read to children. I've never regretted my decision to become a teacher.

Medary School

Who do you admire the most? What did this person teach you?

I really admired my teacher, Mrs. Faist, because she taught my class how to appreciate nature. To this day, I love gardening, visiting the zoo, and bird-watching.

The resident gets an account – FOREVER!

The LifeBio staff will type the story into LifeBio and upload photos (if any are provided).

R34

LifeBio generates a Life Story Summary

Delores

Delores was born in Luther, Michigan. Her father was a farmer and her mother was a school cook. Delores graduated from Luther High School and then attended Michigan State to become a **teacher**. Later, she earned her Master's degree at Capital University. Delores was a passionate teacher and never regretted her decision to pursue a career in education.

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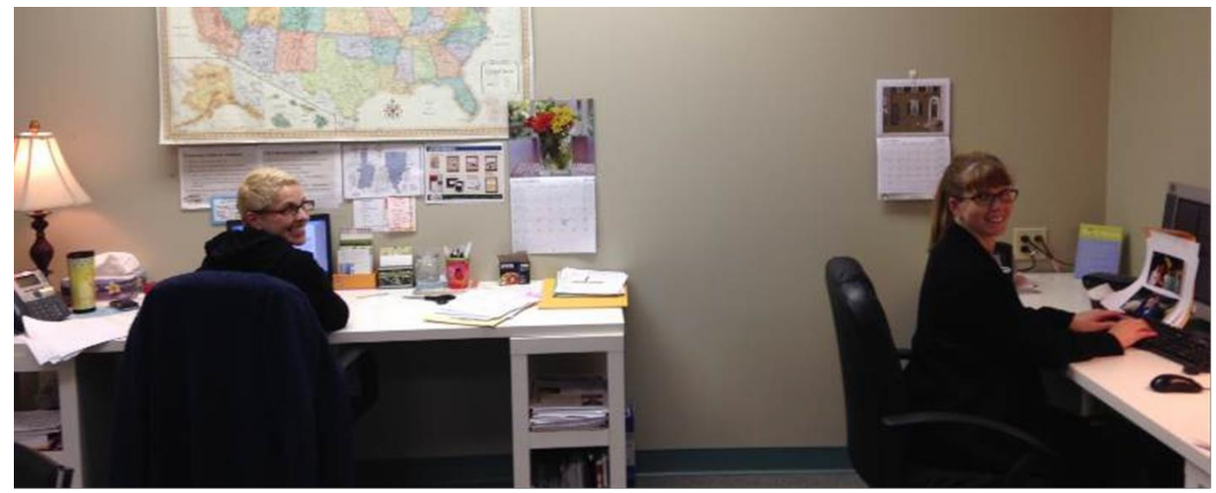
"Every day is a new adventure!"

Let's Talk About...

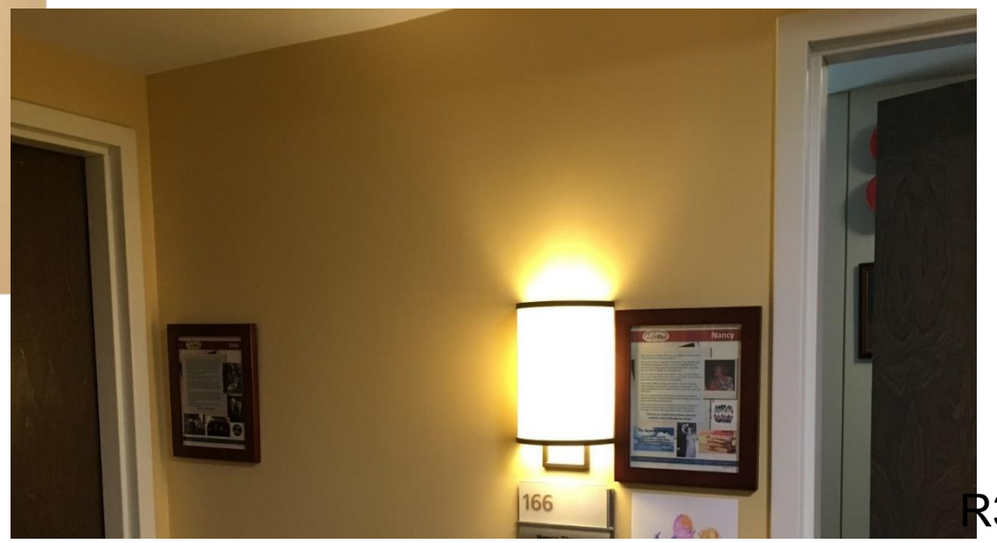
My family
Teaching
Shopping
Bird-watching



The Story Team is ready to serve you! We have a group of personal biographers who will FINISH each story in a beautiful and professional way!

Life Story Snapshots Displayed

Professional & Visible



R36

A few words about HIPAA…

HIPAA, formally known as the Health Insurance Portability and Accountability act, was signed into legislation back in the 90's. Specifically, the HIPAA Privacy Rule created the first national standard to protect personal health information and medical records.

LifeBio is HIPAA Compliant:

- By agreeing to participate in the LifeBio Project, residents consent to allowing *non-medical personal preferences and life history information* to be shared with family, staff, volunteers, and public visitors.

However, absolutely NO medical information or survey opinions will be made public.

- Please Note: The LifeBio Summary ("Snapshot") will have no last names and no birth years included.

- Recommendation: The care plan can be edited to note that the LifeBio Summary ("Snapshot") is an important resource that assists staff in complying with these regulations: person-centered care planning (F636 and F656), personalized activities (F679), and personalizing activities for behavioral health services/dementia (F679).

R38

My name is Delores and my birthday is November 25th

Hometown:
Luther, Michigan

HELPFUL THINGS TO KNOW ABOUT ME…

- My true love is my husband, Curt!
- I have two sons, Jeff and Steve.
- Shopping is my favorite hobby.
- I taught 4th Grade for 30 years in Columbus Public Schools.

LET'S TALK ABOUT…

- Traveling
- Shopping
- Teaching
- Being a mother and grandmother

THINGS TO DO & CALENDAR ACTIVITIES PERFECT FOR ME…

- Paint with watercolors
- Turn on music from the 1950s and 1960s!

- Let's go shopping!
- Plan tea time or a special meal.
- Hold Bible studies, or play classic hymns.

- Outdoor activities, gardening, and watching and feeding the birds are fun!
- Make hummingbird feeders!

- Help me instruct others - I love teaching!
- Watch, listen, or read the news with me!

Using LifeBio in Care Planning…

1. Place the Life Story Snapshot & Action Plan inside the Care Plan.

2. If possible, use the LifeBio Action Plan in weekly staff meetings or huddles.

3. Think about how LifeBio Action Plans can be communicated on 2nd and 3rd shift too.

More Ideas!

Your Role as a Staff Member

- Support the researchers – the research is very important!
- Support the volunteers – help them connect with residents.
- Help the LifeBio Liaison (main contact) when needed.
- Look at the Life Story Books with residents!
- Use the Life Story Snapshots and Action Plans in care planning and daily life.
- Get EXCITED and ENGAGE!

Overcoming Objections

"Who wants to hear about me?"

There is no one else like YOU! Your friends in this community would like to know more about you. You may have family members who would also like to know more about you. You are able to describe the times, places, and people that only YOU are able to share. To family, friends, and the staff at this community, YOU are who they care about!

"My story is too personal."

You don't have to share anything that you don't want to share! You can tell us if certain topics are "Off Limits." We will respect your right to share only what is comfortable to YOU. Just say "PASS" to any question that makes you uncomfortable.

"I am ashamed of the life I have lived."

No one's life has been perfect. Life is like a roller coaster – with both ups and downs. You have gained invaluable experience and lessons learned from the "tough times." Often, the best stories are the ones where you have overcome obstacles!

"I don't have anything to say."

This is not true. The LifeBio process – with the help of a volunteer – is the perfect way to get started! You can tell about historical events through YOUR unique point of view. We are betting you will be surprised by just HOW MUCH you have to share!

"My kids and grandkids already know everything about me."

They only know a part of your story, and this is a good time to build a legacy for the next generation. You are more than just a parent or grandparent – you had a whole life before they were even born! Your family will gain from knowing more about your life as a child, teen, young adult, and more.

"I don't have anyone to give the book to. I don't have any family."

You have a legacy even if you don't have children or grandchildren. There is no one else in this entire world like YOU. You matter to the people at this community who feel like family to you, and they want to have your story recorded. This process is for YOU, and we think you will enjoy it!

Volunteers & Difficult Conversations

What if someone doesn't want to answer for some reason? They should share only what they want to share. Perhaps a memory or time or event is too painful or sad for them. "Only share what you want to share," is a good response.

If they leave out parts of the story, is that okay? Absolutely! The book and summary will still look great if only some information is shared.

What if someone has strong feelings or cries when he or she is sharing?
It is normal for people to feel deeply about their memories. Listen with empathy and caring—sometimes that means just nodding and being silent. A possible response when a life experience was hard… "You made it through a difficult time. I feel that you are a very strong person."

Is there help available if I need it?
Please seek out the site contacts and share your concern. Nurses, the social worker, or the administrator could help you speak with the resident.

Session Activities

Let’s Try It Together…

Now we are going to explore two activities to introduce you to the LifeBio process.

Role Play #1 – Knowing the Story

David

David was born on November 29th in Battle Creek, Michigan. He has one older sister. David married Sandra and they have three children: David Jr., Jason, and Kevin. They also have seven grandchildren.

After graduating from high school, David joined the Air Force as an aircraft mechanic. Working on airplanes came naturally to him. He worked on B58 planes and was also a Strategic Air Command in the Cold War. One of the planes he worked on even broke the 1,000 km speed record!

After leaving the military, David worked as a police officer and then joined the Air National Guard. Another job he enjoyed was working with emotionally impaired children. He was also a volunteer firefighter for 40 years.

David likes trains, both model and real. He also used to build model airplanes. He enjoys shooting and has a license for short wave radios. He used to enjoy playing softball and was able to play one entire season without getting hurt!

David's favorite movies are westerns and old black and white movies. His favorite songs are "Can I Have This Dance" by Anne Murray and "Waltz Across Texas" by Daniel O'Donnell. He likes rock and roll music from the '50s and early '60s, and also likes older country western music. He even wanted to be a cowboy when he was a child!

Let's Talk About...

Air Force

Firefighter days

Trains

Softball

Action Plan Sample

My Name is David and my birthday is November 29th

Hometown:
Battle Creek, Michigan

HELPFUL THINGS TO KNOW ABOUT ME…

- My true love was my wife, Sandra.
- I have three children and seven grandchildren.
- I was an aircraft mechanic in the Air Force.
- I worked as a police officer.

LET'S TALK ABOUT…

- B58s and the airplane that broke the 1000 km speed record
- Volunteer Firefighting
- Trips to Cedar Point
- 1000 Points of Light Award from President Bush

THINGS TO DO & CALENDAR ACTIVITIES PERFECT FOR ME…

- Show Westerns, Jimmy Stewart films, and old black and white movies.
- Help me build a model. Planes and trains are great choices!

- Bring in Nerf toys for safe target practice!
- Help me play wiffle ball or a similar safe version of softball!

- Listen to Anne Murray, Daniel O'Donnell, early 50s/60s music, or older country music with me.
- Show me photographs of trains and B58 planes.

- Armchair travel down Route 66 with me!
- Try to schedule things later in the day or evening– I'm a night owl!

Role Play #2 - Practice Interviewing

Interview each other using About Me questions

When and where were you born? Where have you lived most recently? Describe your childhood home and hometown…

Follow Up Questions…

→Is your hometown the place you were born or someplace else?
→How long did you live there – do you still live in your hometown?
→If you moved away, why? If you stayed, why?
→What is the best thing about your hometown?
→Where would you recommend a newcomer visit – restaurant, park, boutique, other? Why this place?

Role Play #2 – Time to Switch!

Interview each other using About Me questions

Describe the work you have done in your life.

What was your first job? Describe the jobs you have had (around the house, paid work, or volunteering). What was your favorite/least favorite job?

_____

_____

_____

_____

_____

_____

Follow Up Questions…

→What led you to your current career choice?
→Did you go to college or a vocational school? Where?
→What would you consider to be your "dream" job?
→What do you like the most about your current job?
→If you won a million dollars, would you still continue working?

Discussion…

How did it feel to be interviewed?
(Did it feel good to share your story?)

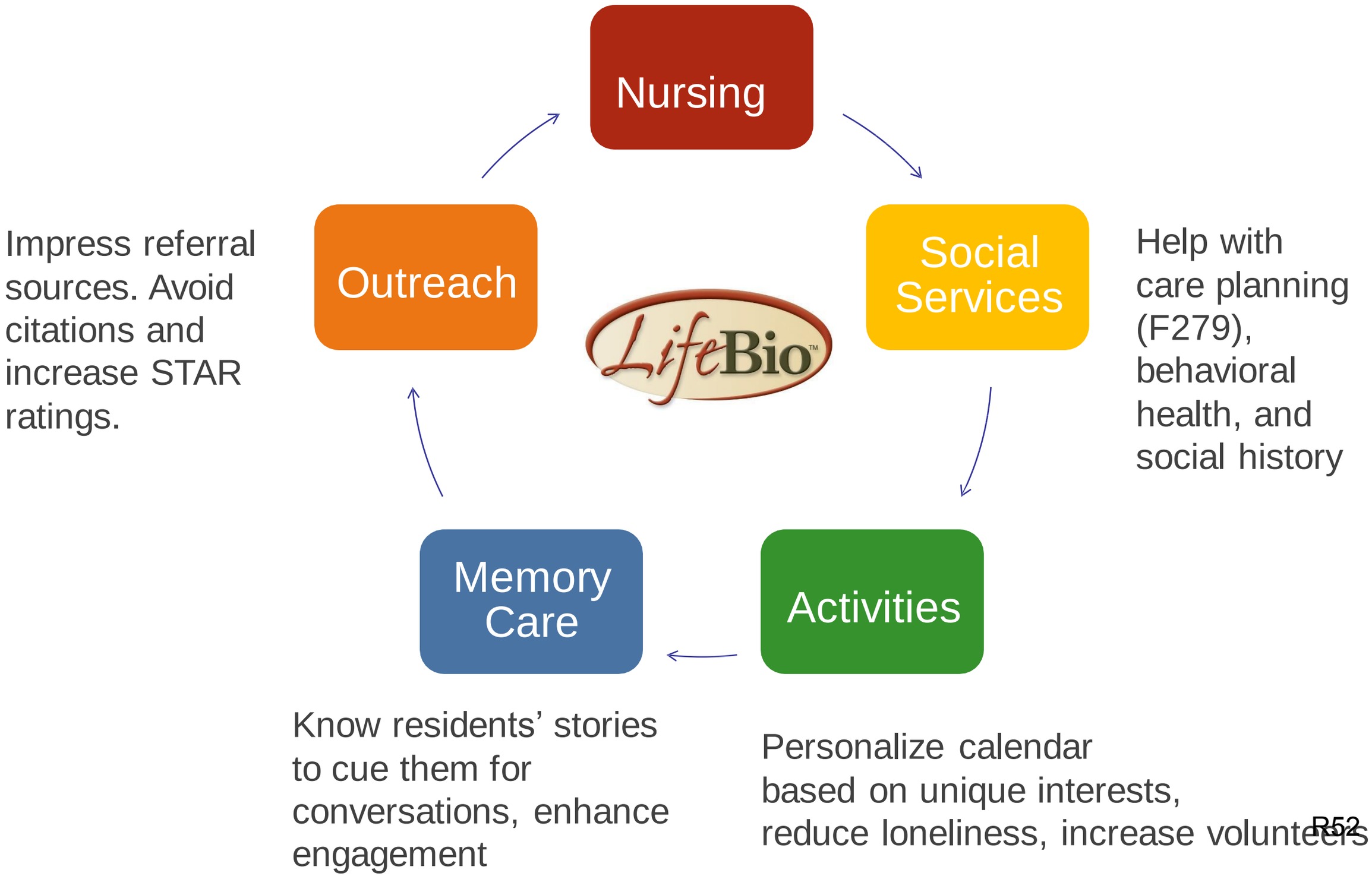
How did it feel to be interviewing someone else?
(Was it hard to stay quiet and not interrupt?)

Did you learn something new?
(Even about someone you thought you already "knew"?)

What do you think residents, family, and volunteers will gain from this process?
(Let's explore that…)

Key Areas Impacted

Impact Health & Wellbeing of Resident, Build Stronger Resident / Staff Relationships
Reduce drug usage by increasing engagement.



Importance of the Research

The Benjamin Rose Institute on Aging will be reaching out to conduct periodic research on this project with staff, residents, family members, and even volunteers.

Your nursing facility has agreed to be involved in the research associated with the LifeBio Project. Please complete surveys when asked to do so in a timely manner.

ENGAGE!

Deep engagement happens between residents, volunteers, family, and staff to finish the Life Story Book and Life Story Summary.

Staff members read the Life Story Summary and use it for conversations and activity ideas.

Family members engage and enjoy the Life Story Book.

Let's Review What We Have Learned…

The LifeBio Project will help capture the life stories of nursing home residents to support your commitment to person-centered care.

As part of this project, the family will receive a book of the resident's life story; and your facility will receive a one-page life summary (known as a "Snapshot") as well as an Action Plan.

Snapshots and Action Plans are meant to be displayed, integrated into the Care Plan – and displayed!

Review Questions 1 - 2

1. What are goals of the LifeBio Project? (Circle one answer)

a. Evaluate dining processes at the nursing facility
b. Capture life story information that will help staff know residents more to help with person-centered care
c. Identify new features of the electronic health record system

2. How can the Life Story Snapshots (1-pagers) and LifeBio Action Plans be used to deliver person-centered care? (Circle the correct answer)

a. Display them outside the person's room so they are visible to the resident, other residents,
b. Read and discuss at least one person's unique Life Story Snapshot and Action Plan during staff meetings or team huddles
c. Improve the comprehensive care plan (and care plan meetings) by using information from the person's Life Story Snapshot and Action Plan.
d. All of the above

CMS Reg 483.40 Review Slide

DEMENTIA

Behavioral Health Services – 483.40/483.24 (F248/Revised F679)

The Centers for Medicare & Medicaid Services in the Behavioral Health Services regulation (483.40) says, the facility must assure "A resident who displays or is diagnosed with dementia, receives the appropriate treatment and services to attain or maintain his or her **highest practicable physical, mental, and psychosocial well-being."**

Activities must be **individualized and customized based on the resident's previous lifestyle (occupation, family, hobbies), preferences and comforts.**

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Review Question 3

3. **Fill in the missing word. The Centers for Medicare & Medicaid Services in the Behavioral Health Services regulation (483.40) says, the facility must assure "A resident who displays or is diagnosed with dementia, receives the appropriate treatment and services to attain or maintain his or her highest practicable physical, mental, and _____ well-being."**

a. normal
b. psychosocial
c. standard
d. good

CMS Reg. 483.21 Review Slide

Comprehensive Person-Centered Care Planning – 483.21 (F272/F636 – F279/F656):

Know the resident's….

1. strengths

2. goals

3. life history

4. preferences

Attain or maintain the "resident's **highest practicable physical, mental, and psychosocial well-being**."

Review Question 4

4. **What are nursing facility staff members supposed to know about residents as part of comprehensive person-centered care planning? (Center for Medicaid and Medicare regulation 483.21)? (Circle the correct answer)**

a. Strengths
b. Goals
c. Life History
d. Preferences
e. All of the above

Review Question 5

5. **Why is life story work useful for person-centered care? (Circle the correct answer)**

   a. Knowing the life story can help staff members have greater feelings of empathy for the nursing home residents.
   b. Talking about the person's life story may help calm or redirect a person with dementia.
   c. Ideas for personalizing activities and interests can result from knowing more about the person's life story
   d. Residents can experience feelings of happiness and satisfaction with life as they have an opportunity to reminisce and use life review
   e. All of the above

Thank you & Congratulations!

You have completed
LifeBio
Getting Started Training

Questions?
Call 1-866-LIFEBIO (866-543-3246) or 937-303-4576.

Email for questions and to submit resident's story information: story@lifebio.com

Welcome to LifeBio Connect

Congratulations on becoming a LifeBio Volunteer!

Introductions

Today we'll review the following:

- What is the LifeBio Project
- Who is Leading the LifeBio Project
- Your Role as a Volunteer
- Benefits of LifeBio
- How it Works
- How to be a Great Volunteer
- Interview Practice
- Safety
- Final Thoughts – Wrap Up

What is LifeBio?

LifeBio brings people of all ages together to:

-- To build friendships

-- To learn from each other

-- To capture life stories

EVERY person has a story to tell.

LifeBio will provide the tools needed for you to visit and to capture nursing home resident's life stories.

Who is Leading the LifeBio Project?

The LifeBio Project is sponsored by the Ohio Department of Medicaid (ODM) and approved by the Centers for Medicare and Medicaid Services (CMS). The project is administered by the Ohio Colleges of Medicine Government Resource Center in partnership with LifeBio, Benjamin Rose Institute on Aging, and Universal Health Care Action Network Ohio (UHCANOhio).

UHCANOhio works closely to recruit and support volunteers like YOU in the LifeBio Project.

Your Role as a Volunteer

- Meet with a resident and interview him or her. Help to create his or her life story using LifeBio's methods.

- This will also help the nursing facility in their goal to deliver "person-centered care."

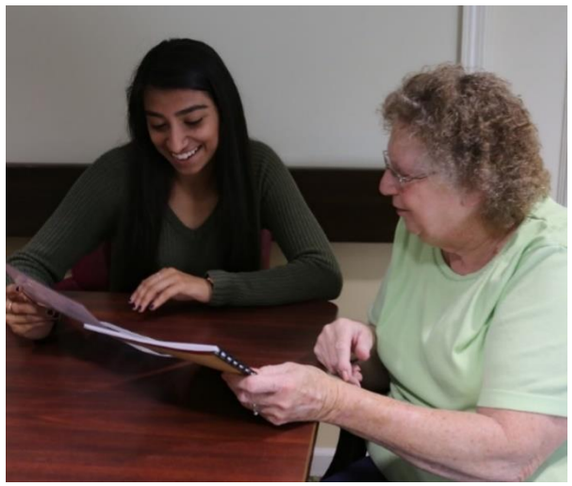
Benefits of LifeBio & Reminiscing

- Life stories teach us about what matters most in life.
- Life stories change people's lives.
- Life stories show us the power of the human spirit.

Health Benefits of LifeBio

INCREASE HAPPINESS

In previous studies, LifeBio resulted in a statistically-significant increase in **happiness and satisfaction with life** for people 65+ (n=50)



FIGHT LONELINESS

Did you know? Social isolation is equivalent to smoking 15 cigarettes a day as a health risk. Both are linked to early death. There are higher rates of heart attack, stroke, and dementia for lonely people.

INCREASE PURPOSE = Reduce hospitalizations

R68

What do YOU think?

Write down what you expect to gain as you listen to life stories.

1.
2.
3.

Share how you expect LifeBio to impact the lives of residents in nursing facilities.

1.
2.
3.

Please share your answers with the group if there is time.

Walking in Everyday People's Shoes

Listen to Mary's Story closely. Feel what it feels like to walk in HER shoes. What's it like to be Mary?

How It Works – Overview

The Interview

- You are matched with a resident for approximately a 1-hour interview
- You may have the chance to conduct 1-5 interviews.

Tools for Interviewing and Gathering the Story Info

- About Me Journal
- Web- www.lifebio.com

R71

Including Photos

- 2 or 3 photos would be great!
- Take a current photo or use old photos

How It Works – What's Delivered

A Life Story Booklet is presented to the resident.

A Life Story Summary is presented. It will be displayed for residents, staff, family, and volunteers to read.

How It Works – Research

The LifeBio Project will include an evaluation led by the Benjamin Rose Institute on Aging. Please be sure you complete the survey after you have completed your interviews.

This is VERY important! The research is key!

How to be a GREAT Volunteer

1. Be enthusiastic and positive!
2. Be a good listener.
3. Be open-minded and non-judgmental.
4. Have good communications skills.
5. Follow the person‘s lead.
6. Take initiative and ask for more information and photos.
7. See it from the resident’s point of view.
8. Be invested in the process.
   Be in the moment!

Interviewing Practice

When and where were you born? Where have you lived most recently? Describe your childhood home and hometown.

Describe the work you have done in your life. What was your first job? Describe the jobs you had (around the house, paid work, or volunteering). What was your favorite/least favorite job?

Who do you admire the most? What did this person teach you? This could be a parent, a famous person, a mentor, a teacher, a person from history, etc.

Reactions

Observations from conducting the interview:

_____

_____

_____

Notes of other tips for interviewing gained:

_____

_____

_____

About Me Journal – Your First Priority!

Spend 1-2 hours (no more than 2 hours) completing the About Me with your partner.

Complete it within 1 week ideally from start to finish.

Once you are done, the LifeBio Liaison at the nursing facility contact will SCAN to connect@lifebio.com
Or MAIL and TRACK to
LifeBio
232 N. Main Street, Suite 2J
Marysville, OH 43040

DOs and DON'Ts for Photos

- Do include 3-5 photos if possible, no more than 15
- Do take photos of original photos with your phone
- Do send to connect@lifebio.com through your phone
- Do make a copy of originals and tape inside About Me
- Do write down captions in the About Me to go with the photos

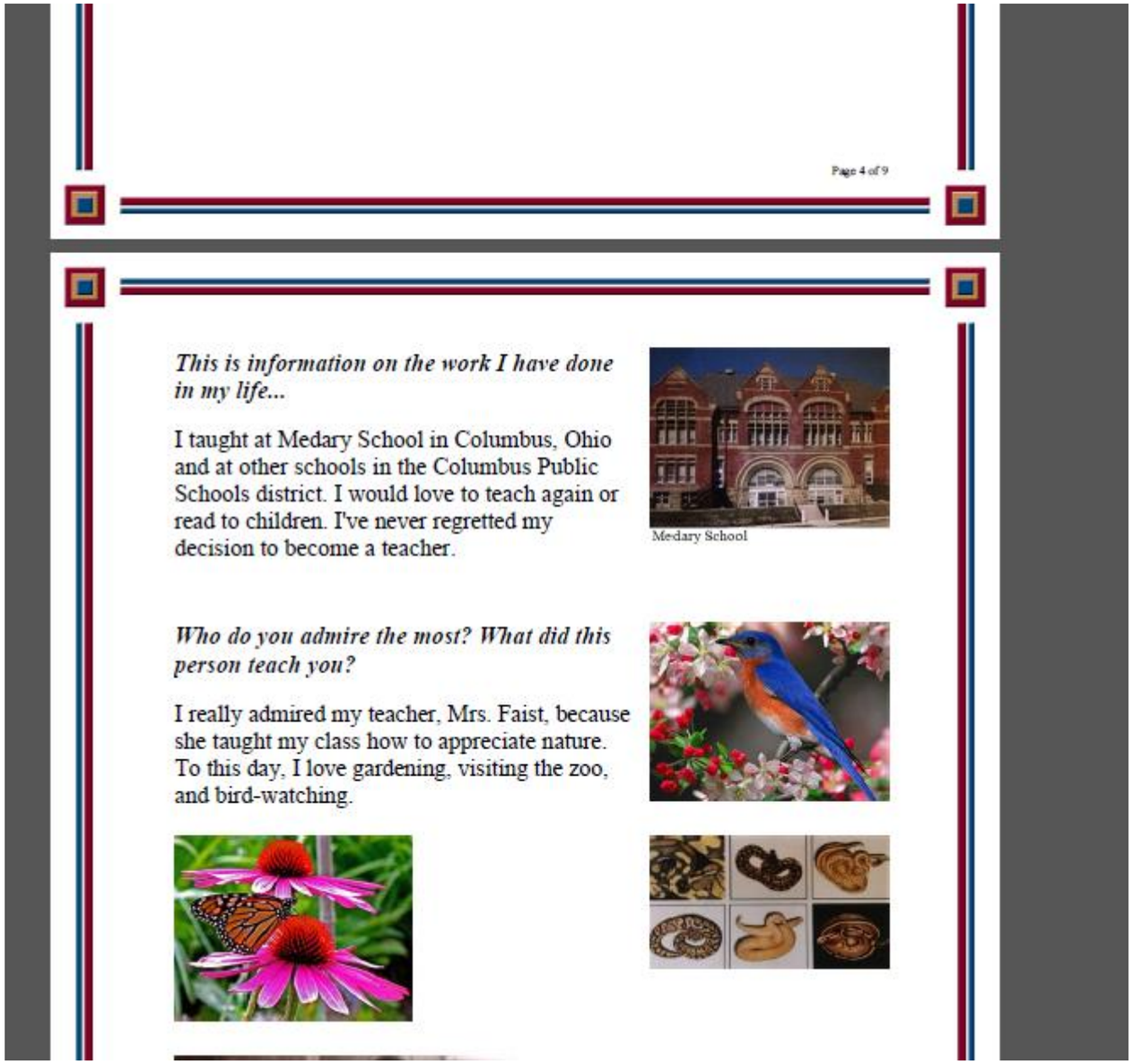
---

- Don't delay the project due to not having photos
- Don't remove the photos from the nursing facility
- Don't share photos on social media

LifeBio System creates Life Story Booklet

The volunteer or LifeBio staff will type the story into LifeBio and upload photos.

LifeBio generates a Life Story Booklet



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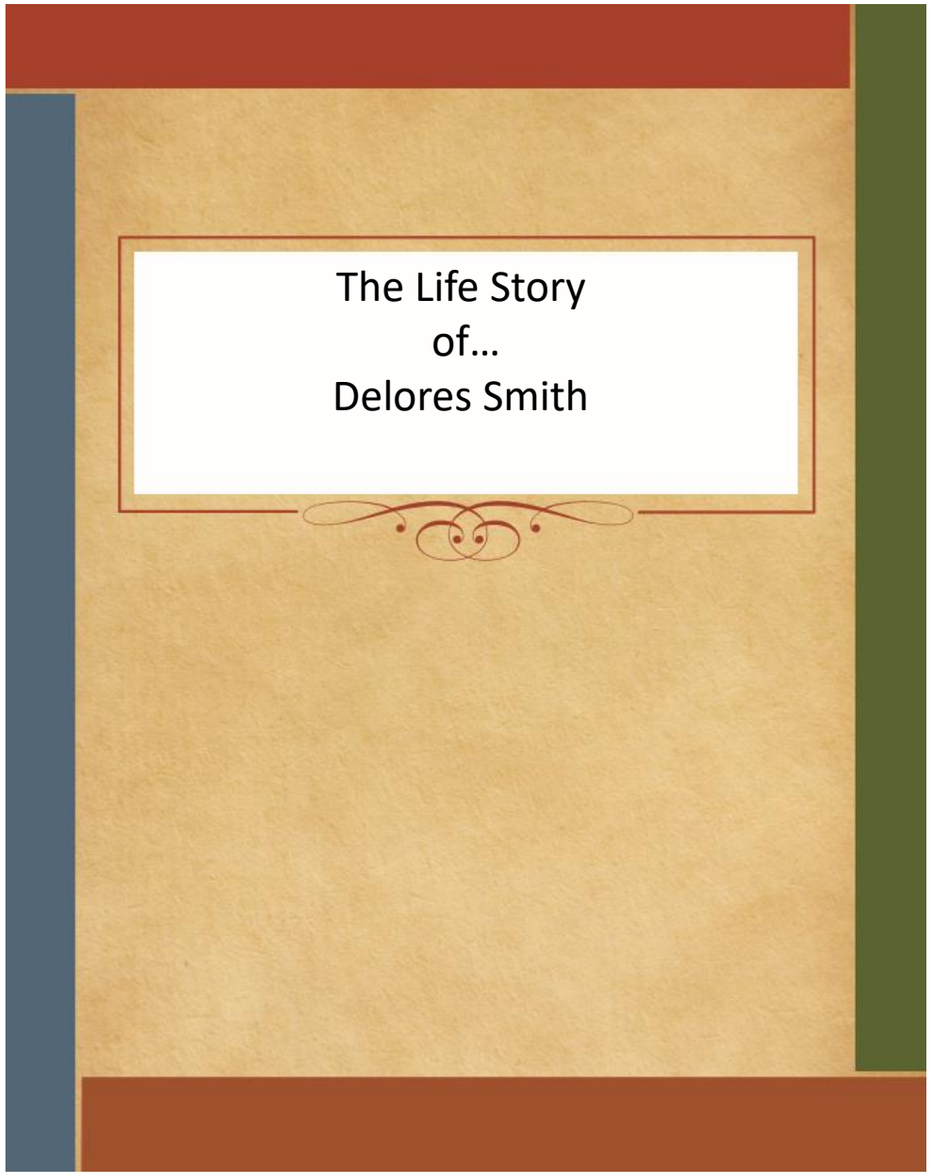
This is information on the work I have done in my life...

I taught at Medary School in Columbus, Ohio and at other schools in the Columbus Public Schools district. I would love to teach again or read to children. I've never regretted my decision to become a teacher.

Medary School

Who do you admire the most? What did this person teach you?

I really admired my teacher, Mrs. Faist, because she taught my class how to appreciate nature. To this day, I love gardening, visiting the zoo, and bird-watching.



Expect approximately a 2-3 week turnaround time between the finished interview and the Life Story Book delivery. A digital proof will be sent to the LifeBio Liaison (staff contact) so the story can be reviewed prior to printing and shipping. R80

LifeBio generates a Life Story Summary

Delores

Delores was born in Luther, Michigan. Her father was a farmer and her mother was a school cook. Delores graduated from Luther High School and then attended Michigan State to become a teacher. Later, she earned her Master's degree at Capital University. Delores was a passionate teacher and never regretted her decision to pursue a career in education.

Delores and her husband, Curt, settled in Westerville, Ohio, and she taught for 30 years in Columbus Public Schools (4th Grade). She loved to travel and visited the Galapagos Islands once!

Delores appreciates family gatherings with her brother and sister, her adult sons and their wives (Jeff and Beth, Steve and Robin), and her teenage grandchildren, Melissa and David.

Delores loves nature and outdoor experiences such as flower gardening and birdwatching (especially hummingbirds!). Delores likes to keep up to date with the news, and she enjoys any opportunity to listen to music, go on trips, or attend Bible studies. Painting is another favorite hobby, as is shopping! Her favorite store is Macy's; she loves to shop for new clothes. Delores enjoys dining out, drinking tea, and eating chocolate!

If there is one wish Delores has, it would be to teach again. She considers teaching her greatest accomplishment.

Every day is a new adventure!

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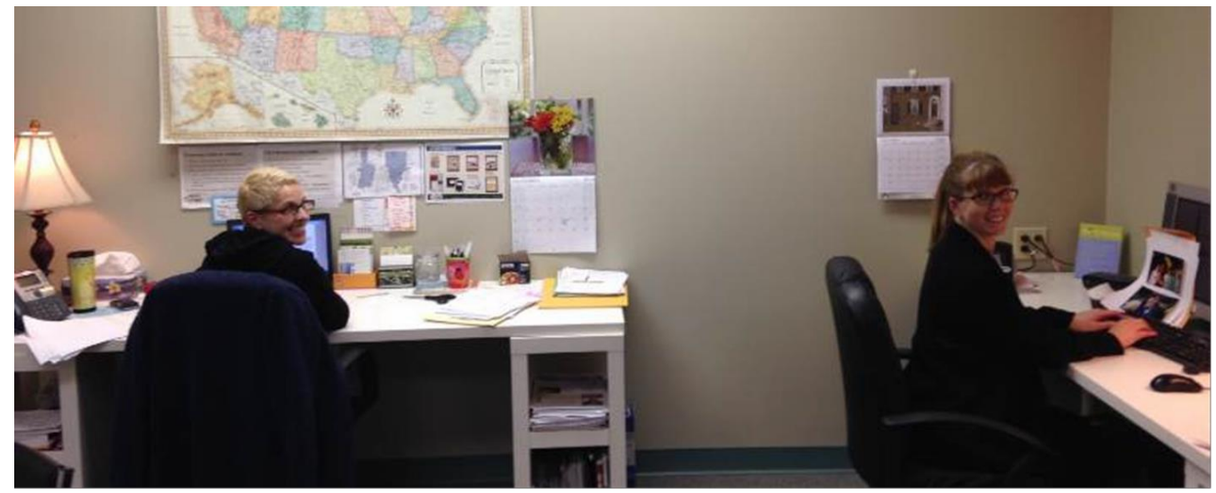
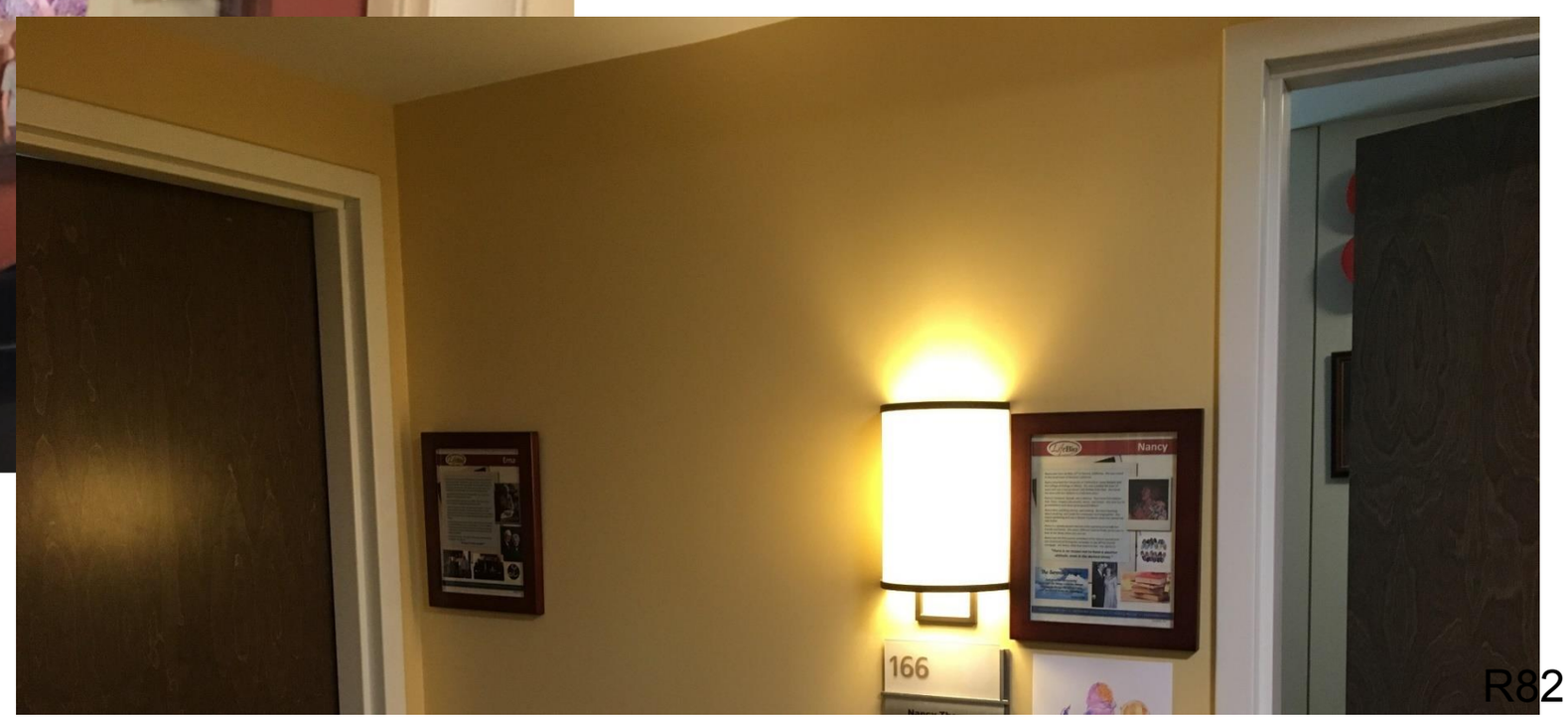


Let's review a Life Story Summary together! As a result of your interview, these will be created for the residents. This also helps the staff to know each person better.

R81

Life Story Summaries

Professional & Visible



Logistics & Details

- Activity Professionals, Social Workers, Nurses, and Key Management People will be trained in advance to USE the person's story in delivering care.
- A main LifeBio Liaison will be named and this will be your primary contact.
- Wear your nametag – it is great for people to know who you are when you are in the building
- Possible times to visit – avoid meal times and popular events/activities (9-11 am, 1-4 pm, 6-7 pm)
- Ideally, you and other volunteers may begin on the same day and be introduced to the LifeBio Liaison at your site at that time.
- There are only *some* residents at a site participating. You will be assigned a person to interview. Be open to a change or to conducting more than one interview.
- Family may be present and they could assist with photos or help a loved one.

Safety is Our #1 Concern

LifeBio Volunteers must always meet in quiet but public settings. Please follow the rules at the nursing facility. Resident doors should remain open so staff members can observe you and your partner during an interview. Discuss safety and particular rules at the nursing facility where you will be located.

Difficult Conversation FAQs

What if someone doesn't want to answer for some reason? They should share only what they want to share. Perhaps a memory or time or event is too painful or sad for them. "Only share what you want to share," is a good response.

If they leave out parts of the story, is that okay? Absolutely! The book and summary will still look great if only some information is shared.

What if someone has strong feelings or cries when he or she is sharing?
It is normal for people to feel deeply about their memories. Listen with empathy and caring—sometimes that means just nodding and being silent. A possible response when a life experience was hard… "You made it through a difficult time. I feel that you are a very strong person."

Is there help available if I need it?
Please seek out the site contacts and share your concern. Nurses, the social worker, or the administrator could help you speak with the resident.

Handling a Negative Reaction

What should you do if the reminiscing process brings up negative feelings for a participant?

Please request assistance from a nursing home staff member.

Final Thoughts – Wrap Up

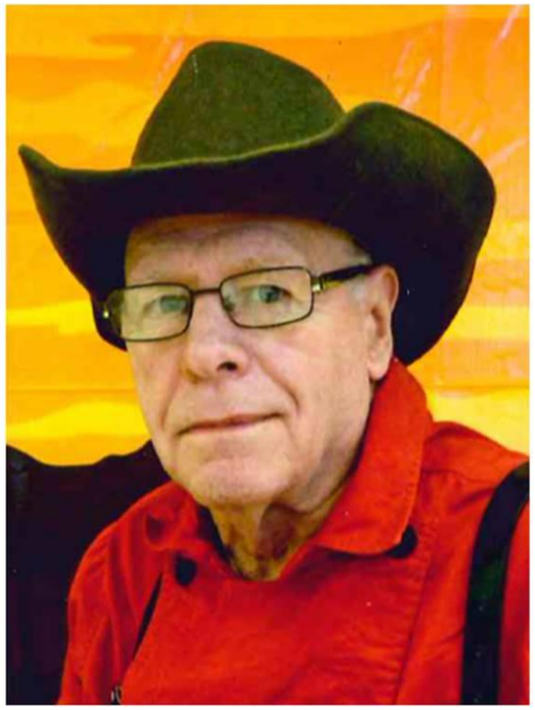
1. Each person is AMAZING and UNIQUE.

2. Emotions Happen!

3. Be Prepared.

4. Express Interest.

5. Stay Open to What May Happen!



Congratulations!

You have completed LifeBio Connect Volunteer Training!

Questions?
Call 1-866-LIFEBIO (866-543-3246) or 937-303-4576.

Email for questions and to submit story information:

connect@lifebio.com

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Resource 4: Staff Presentations Training Page

STEPS TO PRESENTING THE LIFEBIO!

1 Congratulations!

Inside this package are green LifeBio presentation envelopes for people who have participated in LifeBio. This contains…

Life Story Book

Snapshot

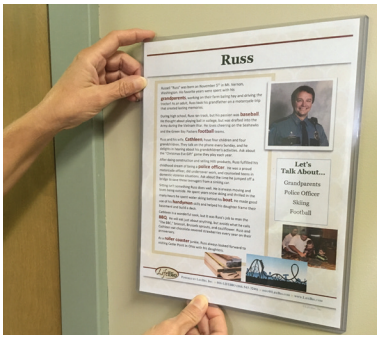
Action Plan

2 Don't delay!

Within 2-3 days of receiving the LifeBio presentation envelope, a team consisting of members of the life enrichment/activity staff and at least one direct care staff member (preferably the one most involved in the direct care of the resident: cna, stna, nurse, social worker, etc. should present the life story book to each person separately. This is an exciting time to celebrate!

3 Read the Snapshot out loud to each person & then display it!

Take a moment to read the Snapshot OUT LOUD with each person. Next, decide if the Snapshot should be displayed outside the person's room on the wall/door (recommended method) OR inside the person's room on a tabletop or bedside (materials included). Make sure the Snapshot is in a location where direct care staff will see and use it.



4 Decide where Action Plans will be made available as a great resource for staff.

The Action Plan is used behind-the-scenes in CARE PLANNING. This has ideas for personalizing activities such as movies, outings, guests, events, and more. Get creative!

5 Use the LifeBio resources.

- Read and discuss Snapshots and Action Plans during team huddles and staff meetings
- Use these tools when training new staff members
- Replicate Snapshots and Action Plans and place inside the Chart/Care Plan (digital versions available)
- Make birthdays special – have residents share their books with staff and others
- Share Snapshots during social activities so residents can get to know one another
- Use the Action Plans to create unique programming – and to match residents who have similar interests

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If any questions arise or if you need HELP planning how best to use the Life Story Books, Snapshots, and Action Plans, please call us at +**1-937-303-4576** or email us at **story@lifebio.com**.

Resource 5: Recruitment Flyer

The LifeBio Connect Experience

Are you willing to help your community and older adults by volunteering a few hours of your time to help people connect as a LifeBio volunteer?

LifeBio Connect brings together younger people and older people to build friendship and to empower older people to tell and share their life stories. Volunteers will have an opportunity to meet a very special older adult in Cuyahoga County, who has a great story to tell.

'LifeBio is one of the most rewarding things you will ever do.'

'Volunteers laugh, cry, and most importantly CONNECT with their senior partner in a heartfelt, life-affirming way.'

The time commitment for the LifeBio Connect Program is approximately a 1 hour visit with a senior or a senior's family member. We are looking for volunteers who can commit to conducting at least 10 interviews over a period of five weeks.

Attend a LifeBio Connect Orientation on....

Date: Monday, May 14, 2018

Time: 4:00 pm – 6:00 pm

Or

Tuesday, May 15, 2018

9:00 am – 11:00 am

Location: Benjamin Rose Institute on Aging

11890 Fairhill Road, Cleveland, OH 44120

The time commitment for the LifeBio Connect Orientation is 1.5 hours.

Please RSVP by May 10, 2018, if you plan to attend the upcoming LifeBio Connect Orientation by calling Yvonne Oliver at 216-241-8422 or email yoliver@uhcanohio.org

Resource 6: Frequently Asked Questions

FREQUENTLY ASKED QUESTIONS

What is the purpose of LifeBio?

LifeBio is a program designed to capture nursing facility residents' life stories. LifeBio utilizes life stories as a positive and powerful way to connect with residents in nursing facilities to ensure they are deeply known by staff members and by you as a volunteer. Every person has a story to tell.

Why are these stories important?

Life stories teach us about what matters most in life. Life stories change people's lives. Life stories show us the power of the human spirit.

What will be my role as a volunteer?

Your role is to meet with at least five (5) residents and help him or her create his or her life story using LifeBio's methods. By helping write the story, staff members in each nursing facility will know more about residents in their care. You are also helping residents record interesting stories, history, and personal experiences for their family and friends to enjoy.

How will these stories collected?

The LifeBio Project will be providing an easy-to use "About Me" booklet to you to gather the life story information on residents enrolled in Medicaid. The About Me booklet is the primary tool that will be used to gather life story information on each participating resident living in a nursing facility involved in this project. There is space in the booklet for you to write down what you hear during your interview. If you prefer to type the resident's story instead of hand writing it, you can do this in the LifeBio web-based system at LifeBio.com.

How will these stories be used?

The Life Story Summary will be available in a predominant place outside or inside of the resident's rooms and is a perfect way for staff members to learn more about each person's unique background. This will undoubtedly lead to new conversations and connections!

Do I need special training as a volunteer?

Yes, Universal Healthcare Action Network (UHCAN) will provide you with a 90 minutes training on the LifeBio program, how to interact with residents and fill out the About Me booklet, and review the policies and procedures involved in being a volunteer for this program.

How are volunteers and residents brought together?

You will be matched with a resident and help him or her create his or her life story using LifeBio's methods. By helping write the story, staff members in this community will know more about residents in their care. You are also helping residents record interesting stories, history, and personal experiences for their family and friends to enjoy.

Why is this a research study?

The research study is designed to determine the impact of LifeBio on residents' health outcomes, residents' and their family members' satisfaction with care, and staff member job satisfaction. The study hopes to show that by using LifeBio and creating a stronger connection between residents and staff, resident's health will be better. If the study shows this to be true, it will provide the necessary evidence to encourage broader use of the LifeBio program.

Who is sponsoring the project?

The LifeBio Project is sponsored by the Ohio Department of Medicaid and is approved by the Center for Medicaid and Medicare Services.

How do I get more information about the LifeBio Program and being a volunteer?

Contact UHCAN Ohio, Yvonne Oliver, 216-241-8422 or email yoliver@uhcanohio.og

Resource 7: Recruited Community Organizations

Organization	County
District 11 Area Agency on Aging	Ashtabula
https://www.volunteermatch.org/	Ashtabula
Ashtabula 211 Referral Services	Ashtabula
Ashtabula Beautiful	Ashtabula
Ashtabula Church of God	Ashtabula
Ashtabula County Community Action Agency	Ashtabula
Ashtabula County Technical and Career (Nursing Programs)	Ashtabula
Ashtabula Senior Center	Ashtabula
Baldwin Walace Center for Community Engagement	Cuyahoga
Baptist Ministers	Cuyahoga
Business Volunteers Unlimited	Cuyahoga
Capri Cafaro, Former Legislator	Ashtabula
Case Western University - Office of Student Affairs - Senior Health - School of Medicine - Center for Civic Engagement and Learning - School of Nursing	Cuyahoga
Catholic Charities	Ashtabula
Cleveland State University - MEDTAPP Program - Office of Student Affairs - Senior Health - Office of Engagement	Cuyahoga
Community Partnership on Aging	Cuyahoga
Cuyahoga Community College (Tri-C)	Cuyahoga
Eliza Bryant Village	Cuyahoga
Fairhill Partners Senior Services	Cuyahoga
Faith Organizations	Cuyahoga
First United Methodist Church	Ashtabula
Greater Cleveland Congregations	Cuyahoga
Hands on Volunteers	Cuyahoga
Jewish Federation of Cleveland	Cuyahoga
John Carroll College- Center for Service and Social Action	Cuyahoga
Kent State University at Ashtabula - Office of Experiential Education & Civic Engagement	Ashtabula
Leadership Ashtabula County, (Health and Human Services Day)	Ashtabula
Legal Aid Society	Cuyahoga
Lorain County Community College Career Center	Cuyahoga
Messiah Lutheran Church	Ashtabula

Miracle Temple Church of God In Christ	Ashtabula
National Association for the Advancement of Colored People (NAACP) William Tarter	Cuyahoga
National Caucus & Center on Black Aging, Inc	Cuyahoga
Neighborhood Leadership Development	Cuyahoga
RSVP	Ashtabula
Senior CareNetwork	Ashtabula
Solon Senior Center	Cuyahoga
St. Nicholas Byzantine Catholic Church	Ashtabula
United Church of Christ	Cuyahoga
vistaleader@ohiocdc.org	Ashtabula
Western Reserve Area Agency on Aging (WRAA)	Cuyahoga
Youngstown State University	Ashtabula