Meaningful Measures

Implementation and development of MYCaW® frailty framework – Phase Two

Meaningful Measures Ltd
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Glossary

- **ADL** - Activities of Daily Living. Activities of daily living (ADLs or ADL) is a term used in healthcare to refer to people's daily self-care activities. Health professionals often use a person's ability or inability to perform ADLs as a measurement of their functional status.
- **CFS (Rockwood)** - The Clinical Frailty Scale (Rockwood), is being used by the NHS to help decide which people are most likely to recover, ranks frailty from one to nine.
- **EMIS** - EMIS Health, formerly known as Egton Medical Information Systems supplies electronic patient record systems and software used in primary care, acute care and community pharmacy in the United Kingdom. EMIS is one of the suppliers approved by the GP Systems of Choice and so funded by the NHS, similar to SystmOne.
- **Frailty** - a person's mental and physical resilience, or their ability to bounce back and recover from events like illness and injury.
- **GHC** - Gloucestershire Health and Care NHS Foundation Trust is an NHS foundation trust which provides physical health, mental health and learning disability services throughout Gloucestershire.
- **ICS/ ICB** - NHS Gloucestershire Integrated Care Board (ICB) is Part of the One Gloucestershire Integrated Care System (ICS). These are structures organising heath care provision in Gloucestershire's NHS.
- **MYCaW®** - Measure Yourself Concerns and Wellbeing is an individualised outcome measure used for evaluating holistic and person-centred approaches to supporting people. It is a short, validated tool that can be routinely incorporated into a consultation to see where a person most wants support or used in an organisation to improve workplace wellbeing.
- **PCN** – Primary Care Network is a collection of GP practices serving a population of 30,000-50,000 people
- **SystmOne** is one of the computer systems available to GPs, similar to EMIS.

Executive Summary

Background:

Approximately 10% of people aged over 65 years and 25% of people over 85 years live with frailty, and this is expected to double by 2045. Gloucestershire Integrated Care System (ICS) has developed several strategies and transformation programmes which inform personalised proactive models of working with people living with frailty. It is, therefore, important to capture the views of patients living with frailty so that Gloucestershire ICS can deliver effective, person-centred services.

MYCaW® is an individualised questionnaire designed for evaluating personalised approaches to supporting people. MYCaW® enables a person to state their concerns, and then to assign a score to this concern and score their wellbeing. A follow-up questionnaire enables changes in reported concerns and wellbeing over time to be captured and also allows for wider reflection on other things happening and the impact for the services received.

Aim of this evaluation:

- **i)** To confirm the acceptability of using the MYCaW® as a core outcome measure within Gloucestershire ICS frailty services to understand what a person most wants support with.
- **ii)** To update the initial MYCaW® concerns framework to enable systematic reporting of personalised data in this sample population.
- **iii)** To investigate how well the frailty services are meeting people's needs and how this may be affected by a persons' level of frailty.

Methods:

Three services supporting people with frailty within Gloucestershire ICS participated in this evaluation- Complex Care at Home (CC@H), South Cotswolds Frailty Service and North and South Gloucester PCN Frailty Service. Patients were assessed using the CFS (Rockwood) and offered the chance to complete a MYCaW® questionnaire during their first session and then three months later. Exclusion criteria for the project were: People living in care homes, people under the age of 18 and anyone not classed as at least mildly frail on the. Data was also collected from healthcare practitioners about their experience of using MYCaW®. Content analysis was used to code the concerns and finalise a frailty concerns framework. Descriptive analysis was carried out on demographic data and frequency of concerns reported. Analytical statistical analysis was used to determine the statistical significance of MYCaW® score changes, sub-analysed for frailty levels.

Results

Demographics: Baseline data was analysed from n=967 people. The average respondents were 85-89 years, White, female and living in Gloucestershire. 191/967 people died before follow-up data was collected but incidence of death was not correlated with the severity of CFS (Rockwood) scores. MYCaW® follow-up data at three months was gained from n=432 people. 45% of the sample were mildly frail, 41% moderately frail, and 14% severely frail.

Types of MYCaW® concerns: A final qualitative coding framework of MYCaW® concerns was developed using 1625 concerns from 967 people. The most frequently reported supercategories of concerns were "Physical" (41%), followed by "Practical" (19%). The top five most frequently reported concerns were i) mobility, ii) managing the household/activities of daily living, iii) other physical problems, iv) housing, v) pains & aches. The severity of frailty had little effect on the types of concerns reported, mobility was most frequently reported irrespective of the CFS (Rockwood).

MYCaW® score changes: Overall, statistically significant improvements in MYCaW® scores ($p<0.001$) for concerns and wellbeing were achieved. Analysis of MYCaW® score changes by severity of frailty, demonstrated statistically significant improvements in concerns and wellbeing ($p<0.001$) for people living with mild (n=200) and moderate frailty (n=159). A smaller number of people were living with severe frailty (n=47) and demonstrated statistically significant improvement in concerns ($p<0.001$) but not in wellbeing.

What was important about the service? At follow-up, people highlighted how important the support, understanding and encouragement was from the staff. People also felt genuinely listened to, appreciated a face-to-face setting and reported that the service helped some of them become more mobile, sociable or independent.

Acceptability of MYCaW® with staff: Feedback from the anonymous survey to professionals using MYCaW®, highlighted the MYCaW® was acceptable and useful in opening conversations. MYCaW® was seen as helpful in understanding what was important to a person, and providing rich, relevant personalised data. There were some logistical issues with integrating the tool within existing electronic systems specific to the operating environment.

Limitations: Ongoing pressures on the health service in the UK may have impacted the amount of data that was possible to collect. It should also be noted that no control frailty group was available to contrast against the services' MYCaW® scores. Lastly, the coding framework was developed using the data from people in Gloucestershire, further use of the tool in other contexts would be useful to ensure the framework is representative of a wider range of people living with frailty nationally and internationally.

Recommendations:

Several recommendations from this work are outlined below.

Recommendation 1: There is ongoing MYCaW® usage: MYCaW® is a key method of establishing the outcomes a service is achieving with a specific cohort of people within Gloucestershire ICS. MYCaW® data should be continued to be collected to benchmark services performance and monitor the key concerns of the population it serves. More data in each level of frailty severity should be collected and coded against the MYCaW® coding framework as standard practice on a yearly basis. Note, if current systems are still a logistical barrier, then other digital versions of MYCaW® do now exist and can be explored.

Recommendation 2: Using MYCaW® data to inform service development: Top concerns generated should be contrasted against current policy and spend decisions within service provision to ensure the optimum services are available to meet the needs of people living with different levels of frailty. Furthermore, this data can be used to identify potential training needs for staff.

Recommendation 3: Reasons for not completing MYCaW® to be documented systematically: Initial and follow-up MYCaW® data was not possible to collect on several occasions. It would be useful to build into the system a way to record why MYCaW® data could not be collected. One simple way of doing this is to enter the reason in the first concern box of the tool. This data could be investigated to determine under what circumstances the data is not able to be collected. It may be that those with the most severe frailty cannot provide responses to MYCaW®, and if so, proxies should be used to provide this data, and if not possible this should be recorded on the form.

Recommendation 4: Pictorial scale to be further tested: An innovation from this project was to create the pictorial scale with smiley faces to accompany the number Likert scale for MYCaW®. Further testing of the understanding, validity and acceptability of this extra tool should be carried out. People with frailty should be asked their opinions of pictorial tool.

Table of Contents

1.0 Introduction **8**

1.1 What is frailty? 8

1.2 National Approach to frailty in the UK 8

1.3 Gloucestershire ICS approach to frailty 9

1.4 Use of the Clinical Frailty Scale (Rockwood) 10

1.5 The use of Measure Yourself Concerns and Wellbeing® (MYCaW®) to capture views of people living with frailty in Gloucestershire 10

1.6 Aim of this evaluation 12

2.0 Method **13**

2.1 Implementation of MYCaW® 13

2.1.1 Development of data collection process 13

2.1.2 Development of digital data capture processes 13

2.1.3 Development of data security processes 13

2.2 Participants and recruitment 14

2.3 Data collection 14

2.4 Data analysis 15

2.4.1 Development of a MYCaW® Frailty Coding Framework using qualitative data 15

2.4.2 Frequency of MYCaW® concerns 16

2.4.3 Follow-up qualitative MYCaW® data 16

2.4.4 Are MYCaW® concerns different depending on severity of CFS (Rockwood) scores? 16

2.4.5 Analysis of MYCaW® quantitative data 17

3.0 Results **18**

3.1 Participant characteristics 18

3.1.1 Clinical Frailty Scores (Rockwood) 20

3.1.2 Frailty levels of those who died during the data collection window 20

3.2 Development of the MYCaW® frailty framework of concerns 21

3.3 Analysis of MYCaW® concerns data 24

3.3.2 Top five individual types of concerns 25

3.4 Analysis of MYCaW® concerns in each supercategory 27

3.4.2 Practical Concerns 0

3.4.3 Mental and Emotional Concerns 0

3.4.4 General Health and Wellbeing concerns 0

3.4.5 Concerns about healthcare and service provision 0

3.5 Analysis of MYCaW® concerns and wellbeing scores 1

3.6 Does the severity of the CFS (Rockwood) score affect MYCaW® concerns or wellbeing? 2
3.7 What other things are affecting people's health? 5
3.7.1 Other things going on in your life split by frailty category 6
3.8 Patient experience of the service – what was most important? 9
3.9 Staff experience of using MYCaW® 13
3.9.1 Improving accessibility of MYCaW® 13
4.0 Discussion 15
4.1 Identifying the needs of people who are living with frailty 15
4.2 Acceptability and accessibility of using MYCaW® in a population living with frailty 16
4.3 Increasing the accessibility of MYCaW® 16
4.4 Creating a standardised framework of MYCaW® concerns for people living with frailty 17
4.5 What impact are the frailty services having for people living with frailty? 19
4.5 Limitations of this work 20
6.0 Recommendations 22
7.0 Appendices 23
Appendix A: Clinical Frailty Scale (Rockwood) 23
Appendix B: Guidance developed by Gloucestershire services in collaboration with Meaningful Measures Ltd regarding how to implement the MYCaW® tool with people living with frailty 24
Appendix C: Consent form 25
Appendix F: Staff feedback from using the tool 31

1.0 Introduction

1.1 What is frailty?

Having frailty refers to a particular state of health often experienced by older people and describes someone's overall resilience and how this relates to their chance to recover quickly following health problems[1]. The impact of frailty can be quite diverse. For instance, it can lead to a loss of resilience in situations which may normally be overcome, a reduction in physical and social activity, increased risks of falls, disability, institutionalisation, and mortality[2]. In the UK, around 10% of people aged over 65 years and over a quarter of people over 85 years live with frailty[1].

1.2 National Approach to frailty in the UK

Frailty is thought to cost the UK healthcare system around £5.8 billion a year[3]. Older people who have frailty are high intensity users of healthcare resources, and the greater the degree of frailty, the more the health care resource use. Han et al. (2019)[3] found that the extra annual cost to the healthcare system per person was £561.05 for mild frailty, £1,208.60 for moderate frailty and £2,108.20 for severe frailty (2013/14 reference costs). It is thought, however, that frailty can be slowed or even reversed if the right prevention and care are provided, this then can lead to improvements in quality of life and saving money for health systems[3].

The average age of the UK population is projected to increase. The number of people over 85 years old in the UK will almost double by 2045[4]. Therefore, governments must plan forward to meet the needs of this older population and this includes supporting those who may become frail. Identifying and supporting people 65 years and over, who live with moderate or severe frailty was made a routine part of the NHS GP contract in 2017/18[5]. NHS GP practices are required to use the Electronic Frailty Index (eFI), to identify patients over 65 years living with moderate and severe

[1] Clegg A, Young J, Iliffe S, Rikkert MO, Rockwood K. Frailty in elderly people. The Lancet. 2013 Mar;381(9868):752–62.

[2] Cunha AIL, Veronese N, de Melo Borges S, Ricci NA. Frailty as a predictor of adverse outcomes in hospitalized older adults: A systematic review and meta-analysis. Ageing Res Rev. 2019 Dec;56:100960.

[3] Han L, Clegg A, Doran T, Fraser L. The impact of frailty on healthcare resource use: a longitudinal analysis using the Clinical Practice Research Datalink in England. Age Ageing. 2019 Sep 1;48(5):665-671. doi: 10.1093/ageing/afz088. PMID: 31297511.

[4] Office for National Statistics) https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/nationalpopulationprojections/2020basedinterim

[5] https://www.england.nhs.uk/ourwork/clinical-policy/older-people/frailty/living-with-frailty/

frailty. There is debate on how useful the eFI is[6] how frailty is conceptualised by medical practitioners[7] and what outcomes measures are suitable to monitor impact of frailty on a person[8].

In an international context, the World Health Organization (WHO) began the "Decade of Healthy Ageing" in 2020 and has embraced the "Integrated Care for Older People" or (ICOPE) approach[9] . ICOPE aims to support healthy ageing by making sure older people's health and social care systems provide integrated and person-centred care. Elements of the ICOPE approaches are being incorporated into NHS England approaches to support older people.

1.3 Gloucestershire ICS approach to frailty

Within the NHS in England, Gloucestershire Integrated Care System (ICS) has developed a number of strategies and transformation programmes which inform personalised proactive models of working with people living with frailty. The ICS Frailty Strategy (2022-2027)[10] focuses on improving resilience, reducing the risk and impact of frailty and the Ageing Well Programme. This is underpinned by a 'One Gloucestershire' strategic approach to embedding personalisation in practice.

Three services supporting people who have frailty within Gloucestershire ICS relevant to this current evaluation are described below:

Complex Care at Home (CC@H) aims to proactively manage patients with complex health needs, including those living with frailty, in the community, who may previously have been high users of primary care and/or urgent care services. The service aims to prevent hospital admissions where possible. CC@H is a proactive model of care support that is run in Cheltenham

[6] Alharbi K, van Marwijk H, Reeves D, Blakeman T. Identification and management of frailty in English primary care: a qualitative study of national policy. BJGP Open. 2020 Apr;4(1):bjgpopen20X101019.

[7] Seeley A, Glogowska M, Hayward G. 'Frailty as an adjective rather than a diagnosis'—identification of frailty in primary care: a qualitative interview study. Age Ageing. 2023 Jun 1;52(6).

[8] Conroy SP, van Oppen JD. Are we measuring what matters to older people? Lancet Healthy Longev. 2023 Jul;4(7):e354–6.

[9] https://www.decadeofhealthyageing.org/find-knowledge/resources/decade-news/detail/the-decade-of-healthy-ageing-a-new-un-wide-initiative

[10] https://glostext.gloucestershire.gov.uk/documents/s84881/Item%209%20-%20Appendix%201%20Frailty%20Strategy.pdf

and Gloucester and the Forest of Dean by a team of Community Matrons, Case Managers, Dementia Matrons,

1.4 Use of the Clinical Frailty Scale (Rockwood)

The CFS (Rockwood)[11] is a widely used holistic clinical measure of a person's level of vulnerability, or frailty. CFS (Rockwood) is generally carried out as part of a holistic assessment for people over the age of 65 years and can be demarcated into mild, moderate and severe – for more information refer to Appendix A[12].

1.5 The use of Measure Yourself Concerns and Wellbeing® (MYCaW®) to capture views of people living with frailty in Gloucestershire

MYCaW® is a validated individualised questionnaire designed for evaluating holistic and personalised approaches to supporting people. It is brief to complete and can routinely be incorporated into a consultation to understand and prioritise what a person most wants support with. MYCaW® provides a way to capturing the voice of people using services. MYCaW® enables a person to designate their concerns, rate the severity of them and their wellbeing. At follow-up the concerns and wellbeing are rated again to enable statistical analysis of score changes to be carried out. Further qualitative follow-up questions ask if there is anything else important going on in a person's life and what has been most important about the service they have received[13],[14],[15],[16]. MYCaW®, therefore, generates both qualitative and quantitative data.

In 2021, MYCaW® was piloted as a core monitoring tool by the Gloucestershire Clinical Commissioning Group, (now Gloucestershire Integrated Care Board) to understand what matters to people living with frailty in Gloucestershire. Gloucestershire ICS services champion a person-centred approach and MYCaW® is a person-centred outcome measure within this area, helping people at many different levels within the NHS to understand better *'what matters'* to the person

[11] Rockwood K et al (2005) A global clinical measure of fitness and frailty in elderly people. CMAJ 173: 49-495.

[12] https://www.bgs.org.uk/sites/default/files/content/attachment/2018-07-05/rockwood_cfs.pdf

[13] Jolliffe R, Collaco N, Seers H, Farrell C, Sawkins MJ, Polley MJ. Development of Measure Yourself Concerns and Wellbeing for informal caregivers of people with cancer—a multicentred study. Supportive Care in Cancer. 2019;27(5).

[14] Jolliffe R, Seers H, Jackson S, Caro E, Weeks L, Polley MJ. The responsiveness, content validity, and convergent validity of the Measure Yourself Concerns and Wellbeing (MYCaW) patient-reported outcome measure. Integr Cancer Ther. 2015;14(1).

[15] Seers HE, Gale N, Paterson C, Cooke HJ, Tuffrey V, Polley MJ. Individualised and complex experiences of integrative cancer support care: Combining qualitative and quantitative data. Supportive Care in Cancer. 2009;17(9).

[16] Polley MJ, Seers HE, Cooke HJ, Hoffman C, Paterson C. How to summarise and report written qualitative data from patients: A method for use in cancer support care. Supportive Care in Cancer. 2007;15(8).

living with frailty. Initially MYCaW® was implemented in the Complex Care at Home service (CC@H) and the South Cotswold Frailty Service (SCFS), and the scope was extended in 2022 to include data from the North and South Gloucestershire Frailty service.

An earlier phase of the work to implement MYCaW® within the above Gloucestershire services reported that this tool had been successfully used within frailty services[11]. MYCaW® data demonstrated that the CC@H and SCFS showed a statistically significant positive improvement the average MYCaW® concerns and wellbeing scores. This initial report also generated a first iteration of a qualitative framework of MYCaW® concerns, showing the themes and patterns in the needs of people living with frailty. These initial findings enabled commissioners and those developing services to shape provision to best meet the needs of people living with frailty in their communities.

1.6 Aim of this evaluation

There are three related aims to the second phase of the evaluation:

iv) To confirm the acceptability of using the MYCaW® as a core outcome measure within Gloucestershire ICS frailty services to understand what a person most wants support with

v) To update the initial MYCaW® concerns framework to enable systematic reporting of personalised data in this sample population.

vi) To investigate how well the frailty services are meeting people's needs and how this may be affected by a persons' level of frailty.

2.0 Method

2.1 Implementation of MYCaW®

2.1.1 Development of data collection process

The clinical teams, management, and members of Meaningful Measures Ltd refined and built on the implementation process during monthly meetings, with a particular focus on high quality data collection and reporting. Four training sessions on the administration of MYCaW® for patient facing staff were provided by Meaningful Measures Ltd. Meaningful Measures Ltd addressed any issues with collecting data from a population living with frailty and produced a set of guidance notes (see Appendix B for these). These guidance notes covered how to ensure data was collected which captured the patient's voice and scenarios where it may not be appropriate to collect data. Guidance was also given for instances where it was appropriate for members of staff to capture the concerns of patients who may not be able to determine these themselves (due to extreme frailty or dementia).

2.1.2 Development of digital data capture processes

During the project work and meetings, Business Intelligence (BI) staff within the CC@H and SCFS teams, in partnership with Meaningful Measures Ltd, were also able to develop their digital systems to capture the MYCaW® data and produce reports. A template was created for EMIS and SystmOne using temporary codes for the MYCaW® questions, which allowed individualised concerns stated on the first MYCaW® form to appear on the follow-up form, without having to refer back to the patient's notes. Reporting protocols to create an excel file of data for analysis by Meaningful Measures Ltd from the EMIS and SystmOne templates were then developed.

2.1.3 Development of data security processes

MYCaW® data was cleaned by the BI team to remove any identifiers (e.g. names/ locations). Care was taken to ensure data transmission was done in a secure way (via password protected Excel file sent to a secure NHS England & Improvement email address held by Meaningful Measures Ltd). Meaningful Measures Ltd also ensured compliance with the NHS Data Security Protection Toolkit to enable appropriate processes in terms of digital security, storage and management of data.

2.2 Participants and recruitment

Participants were recruited into this project by their use of the CC@H and SCFS services and North and South Gloucester PCN Frailty Service. All people within these services with a generated CFS(Rockwood) were eligible to participate with the following inclusion criteria:

- Adults living in the community and living with frailty who were under the care of frailty services across a variety of settings – specifically CC@H, the SCFS, and North and South Gloucestershire PCN Frailty Nurses/Matron in primary care (people who were eligible for a CFS (Rockwood) assessment).
- Services working with adults living with frailty in the community, ideally working in a personalised way e.g., using health coaching and personalised care and support planning.

Exclusion criteria included:

- People living in care homes
- People under the age of 18
- People not classed as having at least mild levels of frailty on the CFS(Rockwood)

Participation was optional and information at the top of the MYCaW® questionnaire was shown and/or read to all eligible participants. People were given the chance to opt out of the project at this point and not provide their data for analysis by Meaningful Measures Ltd. See Appendix C for further details of consent form.

2.3 Data collection

Levels of frailty: Between November 2020 and June 2023, CFS (Rockwood) data was collected during the initial assessment point when a person first accessed the frailty service, and the resultant score was used to determine the severity of frailty experienced by the patients.

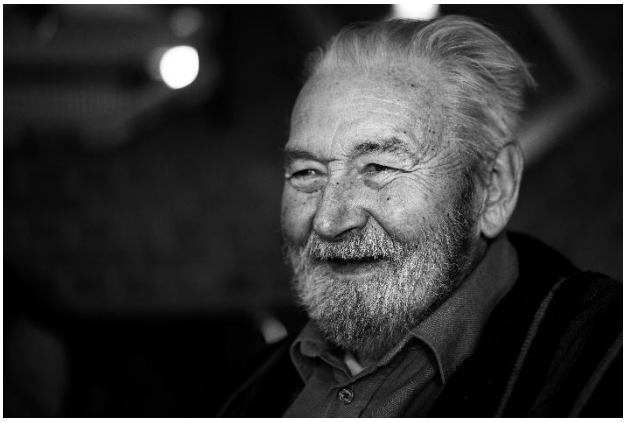
MYCaW®: Baseline MYCaW® data was collected by operational teams including community matrons during their first or second session with a patient. Follow-up MYCaW® data was collected approximately 3 months later, where possible. If a person passed away before follow-up data collection this was noted. If data was collected at a face-to-face consultation, paper forms which a patient could write on were used. Written responses from the paper form were photographed on a community matron's work phone and the data entered into the patient's digital

record by an administrator and the photo of data deleted. For consultations via phone/video call, verbatim MYCaW® responses were typed into SystmOne or EMIS by the consulting healthcare professional.

Acceptability of MYCaW® by professionals: In September 2021 a short anonymous survey was sent via email, to the staff team within the CC@H and SCFS using MYCaW®. This questionnaire was repeated again in June 2023. The survey aimed to understand if MYCaW® was suitable to use in their work environment, was acceptable to use with patients and if there were any scenarios in which MYCaW® did not work with patients. Furthermore, staff were asked if there were any practical issues inputting data into SystmOne or EMIS or if they had any other comments about MYCaW®. Responses were analysed using content analysis.

2.4 Data analysis

The MYCaW® and CFS(Rockwood) datasets were checked and cleaned as necessary e.g. data which did not have follow-up scores was identified so it was not included in the quantitative analysis. The sections below describe the different stages of data analysis carried out.



2.4.1 Development of a MYCaW® Frailty Coding Framework using qualitative data

The first framework of MYCaW® concerns was developed in 2007 [17] and updated in 2015 [18] using data from 1,108 people living with cancer. Parts of the original cancer framework were, therefore, not relevant to people living with frailty. Using the MYCaW® concerns data from people living with frailty, collected in this project, iterative rounds of independent deductive content analysis and coding were carried out.

Initially all relevant coding categories from the original MYCaW® concerns framework were identified, and redundant ones were excluded. Whilst carrying out data analysis, some existing

[17] Polley MJ, Seers HE, Cooke HJ, Hoffman C, Paterson C. How to summarise and report written qualitative data from patients: A method for use in cancer support care. Supportive Care in Cancer. 2007;15(8).

[18] Jolliffe R, Seers H, Jackson S, Caro E, Weeks L, Polley MJ. The responsiveness, content validity, and convergent validity of the Measure Yourself Concerns and Wellbeing (MYCaW) patient-reported outcome measure. Integr Cancer Ther. 2015;14(1).

categories were expanded or adapted to accommodate different contextual information. New categories were also developed if an existing category was not available to be adapted and there were at least 10 similar mentions of a concern. A detailed description of what the researchers included in each category was recorded as categories were adapted or developed, to enable category inclusion criteria to be produced. All new categories were located within the appropriate supercategory and a final review of whether the supercategory names and descriptions were appropriate was carried out.

To test the usability of the final frailty framework, 989 concerns from people living with frailty were independently coded by RB, a researcher from Health Innovation Wessex. Using a "naïve" researcher - with no prior involvement in development of the framework or data collection - enabled a completely fresh perspective on the usability of the frailty framework to be gained. Any discrepancies were noted and resolved through discussion between RB, MP and HS, to produce the final version of the frailty framework. Furthermore, the inter-rater reliability of concerns coding between RB and MP was calculated to determine the level of coding agreement.

2.4.2 Frequency of MYCaW® concerns

To understand the type of concerns reported by people using the frailty services, content analysis was then conducted using the MYCaW® frailty coding framework on all the MYCaW® 'concerns and problems' reported, irrespective of whether there was follow-up data.

2.4.3 Follow-up qualitative MYCaW® data

The follow-up MYCaW® form has two feedback questions which people can provide open responses to; '*What other things are affecting your health?'* and '*What has been most important for you about the service you have received?'*

These questions allow patients to identify any confounding factors which may impact on how well they respond to support from the frailty services, as well as highlighting the qualities of the services which have been most valued. For each question, data was categorised against existing categories and refinements were made as necessary. The frequency of responses in the categories were also analysed.

2.4.4 Are MYCaW® concerns different depending on severity of CFS (Rockwood) scores?

Each person's CFS (Rockwood) score was designated as either a mild (score of 5 or less), moderate (score of 6), or severe (score of 7 or more). The MYCaW® dataset was stratified

according to the CFS (Rockwood) categories to create three subsets of MYCaW® data relating to the categories of clinical frailty. In each subset, the frequency of MYCaW® concern categories were identified to establish prevalence of specific concerns in relation to clinical frailty. These subsets of concerns could then be compared to identify if the prevalence of types of concerns change as the severity of frailty increases.

2.4.5 Analysis of MYCaW® quantitative data

Descriptive data of the services and service users (non-identifiable demographics of 5-year age-band, gender, ethnicity, three letters of postcode) was analysed by calculating percentage frequencies of key categories of data.

CFS (Rockwood) scores: the mean baseline score was calculated for the whole dataset, and for each frailty subset.

MYCaW® scores: the mean changes in concerns and wellbeing scores at baseline and follow-up were calculated when baseline and follow-up data (paired data) were available for a person. Statistical analysis was carried out to determine if the changes in scores at follow-up were significant ($p \leq 0.05$). Data was parametric, therefore a paired two-tailed t-test was used. T-tests were performed on the whole data set (the two services combined), individually for each service and then for the whole data set split three ways according to CFS (Rockwood) categories of mild, moderate and severe frailty.

3.0 Results

3.1 Participant characteristics

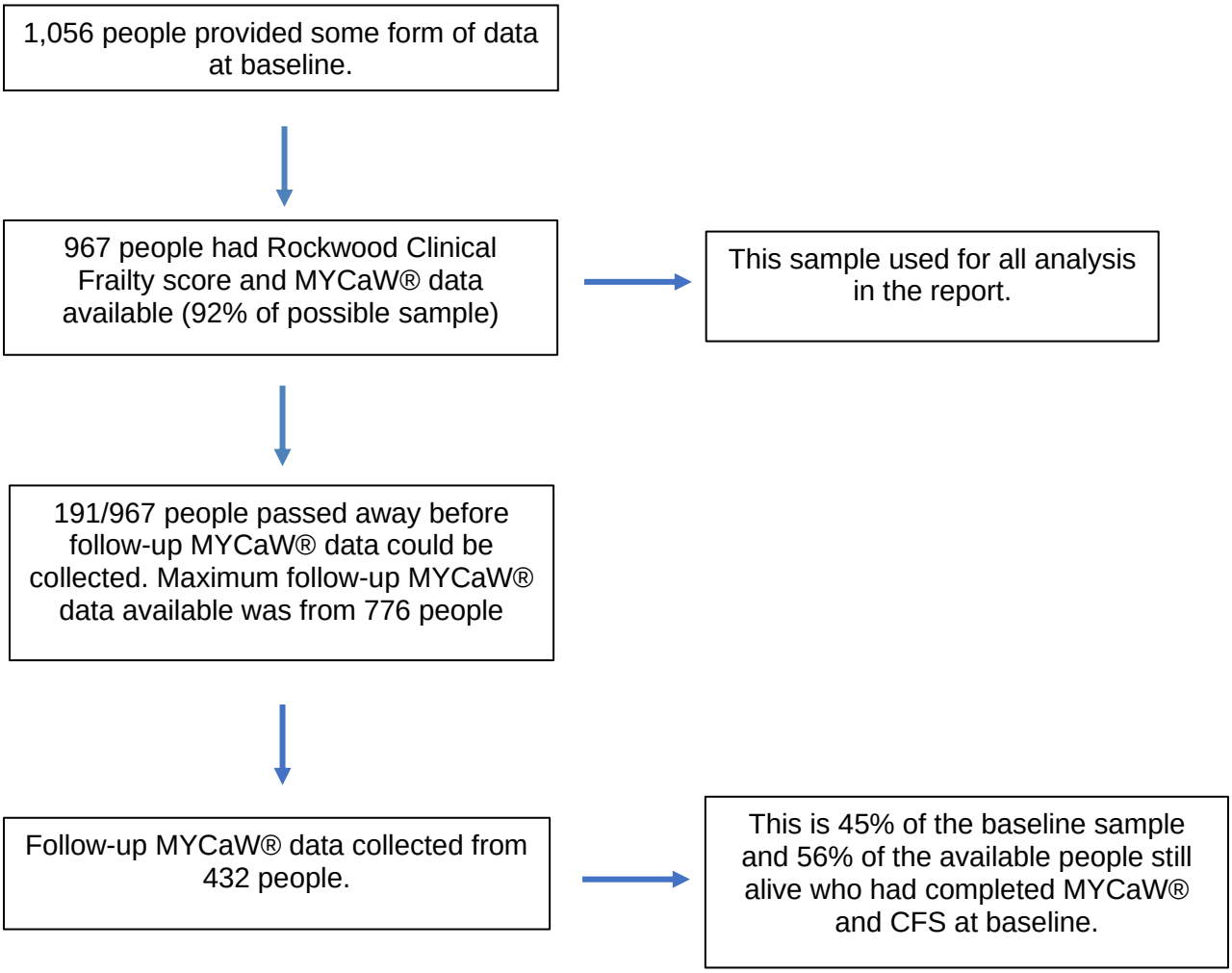
Data was received from 1056 patients, 99% of which came from the Gloucestershire area. The distribution of data according to patients age, gender and ethnicity is shown in Table 1 below.

Category		Percentage (%)
Gender	Female	59.6
	Male	40.4
	Not stated	0
Age (years)	30-39	0.3
	40-49	1.6
	50-59	2.6
	60-69	6.3
	70-79	20.3
	80-89	43.7
	90-99	20.5
	100+	4.7
Ethnicity	White	52.7
	Non-white	21.1
	Not stated	25.9
	Refused	0.3

Table 1. Demographics for the people providing data (n=1056)

The modal participant was 85-89 years old, female (59.6%), White, living in Gloucestershire, UK.

Figure 1. Numbers of people included in data analysis at different stages of the evaluation



To understand how many people's data was analysed compared to how many people entered the project, the flow of numbers is described in Figure 1 above. This takes into account the number of people who passed away after providing baseline data and before being able to provide follow up data.

3.1.1 Clinical Frailty Scores (Rockwood)

CFS (Rockwood) scores were available for n=967 people who had also completed a MYCaW® form. The mean CFS (Rockwood) score was 5.5 (SD 1.7), the modal score was 6 (37.4%), the range of scores was 1 to 9. See table below for percentage splits for Mild, Moderate and Serve Frailty.

Rockwood Frailty score	N value	Percentage (%)
Mild (1-5)	440	45
Moderate (6)	393	41
Severe (7-9)	134	14

Table 2. CFS* (Rockwood) *for people living with frailty n=967 who completed MYCaW® concerns.

It was noticed that the CC@H service had a higher proportion of patients with mild frailty and a lower proportion of patients living with severe frailty, compared to the overall distribution of frailty scores. SCFS, therefore, had a higher proportion of people classified as moderately or severely frail.

	Number of people providing baseline concerns with frailty score		
	Mild	**Moderate**	**Severe**
All n=967	45%	41%	14%
CC@H n=675	52%	37%	11%
SCFS n=292	31%	49%	20%

Table 3. Proportion of people in each service living with either mild, moderate or severe frailty

This difference in proportion of people living with mild, moderate or severe frailty is also demonstrated in the comparison of mean scores for CC@H and SCFS in Table 4 below.

	Mean Frailty scores (SD)			
	All	**Mild**	**Moderate**	**Severe**
CC@H	5.3 (1.9)	4.5 (0.7)	6 (0)	7.2 (0.4)
SCFS	5.9 (0.9)	4.9 (0.4)	6 (0)	7.3 (0.6)

Table 4. Mean CFS (Rockwood) for people in each service living with either mild, moderate or severe frailty

3.1.2 Frailty levels of those who died during the data collection window

191 people (18% of the baseline sample) died during the course of the data collection. 83% were in the CC@H service, 17% were in the SCFS. 56% were classified as living with mild frailty, 35% moderate and 7% living with severe frailty. Incidence of death was, therefore, not correlated to the severity of frailty. Neither were there any differences in this pattern of frailty severity between the CC@H and SCF services.

3.2 Development of the MYCaW® frailty framework of concerns

Having a coding framework provides a standardised approach to analysing and comparing the frequency of individualised concerns across different services or geographical locations. After two rounds of robust independent analysis of 989 concerns from 629 people, and testing of the framework on additional independent researchers (see Figure 2 below), a final version of the framework of MYCaW® concerns from people living with frailty was produced (see Table 5) containing five main supercategories split into 36 specific categories.

Figure 2. Process of developing the framework of concerns from people living with frailty

Phase 1 (November 2020 – September 2021)

546 MYCaW® concerns from 201 people living with frailty.

Independent deductive content analysis by two researchers to develop pilot framework.

Pilot framework independently tested by third researcher for usability. Discrepancies and ambiguities identified, discussed and resolved.

Draft MYCaW® framework for people living with frailty developed.

Phase 2 (October 2021 – Feb 2023)

Additional 443 MYCaW® concerns from 319 people living with frailty added to dataset. Draft MYCaW® framework test with full dataset of 989 concerns from 629 people.

Independent deductive content analysis by a third independent AHSN researcher. Discrepancies and ambiguities identified, discussed, and resolved.

Inter-rater reliability score calculated and final MYCaW® framework for people living with frailty developed.

The evolution of the framework can be reviewed in Appendix D and below in Table 5 (and Appendix E), the full frailty framework of MYCaW® concerns of people living with frailty is described.

Theme	Code	Category
T1- Mental and Emotional Concerns Includes concerns relating to psychological and emotional issues. It excludes physical concerns.	T1a	Confidence issues
	T1b	Depression or low mood
	T1c	Mental health concerns
	T1d	Anxiety and worries
	T1e	Sleep problems
	T1f	Family and relationships
	T1g	The future
	T1h	Loneliness, isolation and bereavement
	T1i	Dementia/memory problems/confusion
	T1j	Lack of motivation
T2- Physical Concerns Includes concerns relating to physical aspects of a person.	T2a	Diabetes or prediabetes
	T2b	Pains or aches
	T2c	Other physical problems or concerns
	T2d	Energy levels or fatigue
	T2e	Weight changes
	T2f	Continence
	T2g	Sight and hearing
	T2h	Mobility
	T2i	Falls or balance issues
	T2j	Breathing problems
T3-Healthcare and service	T3a	Support and information

provision concerns Includes concerns relating to healthcare, support and external services.	T3b	Healthcare or social care provision
	T3c	Physiotherapy and strength
	T3d	Medication
T4-Concerns about General Health and Wellbeing Includes concerns about wider issues around living well and regaining or maintaining one's wellbeing.	T4a	Physical activity or exercise
	T4b	General health and wellbeing
	T4c	Nutrition and diet
	T4d	Getting out
	T4e	Independence
	T4f	Social interaction
T5-Practical concerns Includes data about non-health related concerns.	T5a	Finances
	T5b	Housing
	T5c	Managing the household / assistance with daily activities of living
	T5d	Transport
	T5e	Other practical concerns
	T5f	Digital
T6- Concerns that can't be coded	T6	Use this code when: ● Concerns not completed due to issues with dementia, cognition or a person's loss of ability to generate a concern for themselves. ● 'Declined' or 'none' written down ● Concerns without enough context to code ● Items written as update not as a concern

Table 5. Final framework of MYCaW® concerns for people living with frailty

In the end, eighteen categories were removed from the original MYCaW® framework as they were not relevant to this sample population. This included removing a whole theme - Hospital Cancer Treatment Concerns.

Nine categories were kept the same, where the concerns were common across both groups of people. A further nine categories from the original framework were adapted or amalgamated to cater for different contextual information.

Twenty-two new categories were added, many categories being more specific to issues experienced with frailty, such as mobility and falls, medication issues, continence, healthcare and social care provision, independence, digital concerns, managing the household and daily living.

After the final round of developing the frailty framework, the coding by MP and RB were compared and analysed for inter-rater reliability. A Kappa score of 0.905 was achieved denoting a very high level of agreement in coding between the researchers.

3.3 Analysis of MYCaW® concerns data

The following section details the analysis of MYCaW® concerns for the combined dataset of (n=967). Patients had the opportunity to list up to 2 concerns on the baseline MYCaW® form, hence the total number of concerns analysed was1625. 84% patients were able to complete the MYCaW® form themselves, 14% needed help from staff to scribe on their behalf and 2% of forms were completed by proxy people (i.e., informal caregivers scribing on behalf of their relative or friend). The data was compared for frequency of supercategories for people designated as living with mild, moderate or severe frailty and there were no significant differences in trends to report. So irrespective of frailty levels, the following data represents the general distribution of concerns that people are experiencing.

The frequency of concerns in each supercategory is shown in Figure 3 below as a percentage and shows that there are twice as many concerns relating to physical issues, then anything else.

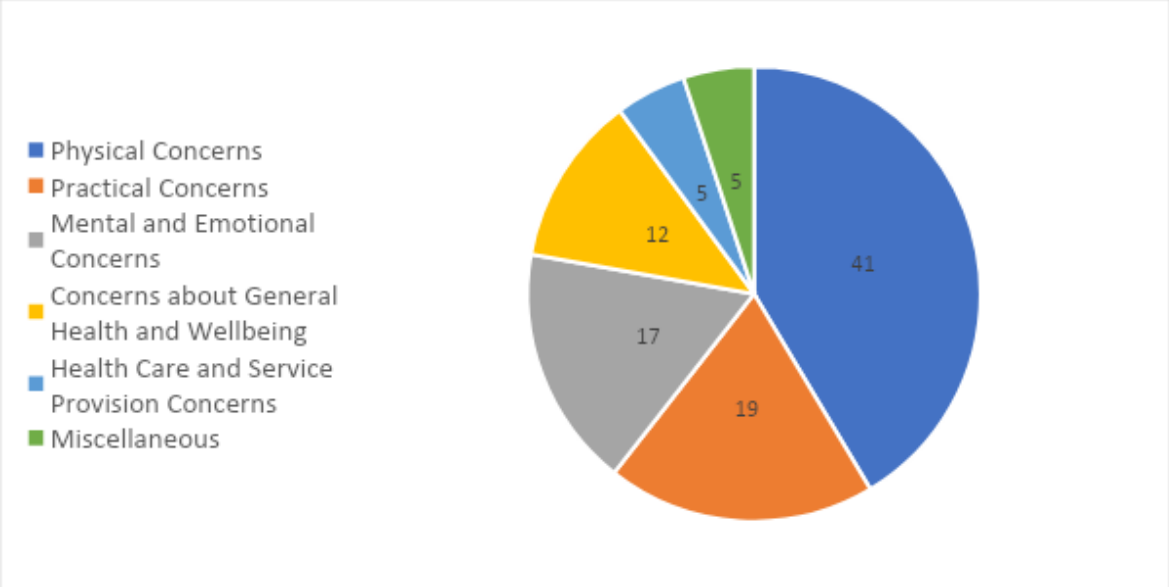


Figure 3. Percentage of concerns in each MYCaW® Frailty coding framework supercategory

3.3.2 Top five individual types of concerns

Across the whole dataset we also identified the top 5 individual concern categories reported by people living with frailty. Unsurprisingly concerns about mobility were most frequently reported. It is worth noting that concerns related to managing the household and activities of daily living as well as concerns with housing are key social determinants of health. Therefore, support given to these concerns is likely to support improved health and wellbeing for these people living with frailty.

Category	% dataset n=1625
Mobility	15
Managing the household/assistance with daily living	9
Other physical problems/conditions	6
Housing	6
Pain/aches	5

Table 6. Top 5 scoring concerns overall

There was also very little difference in how the severity of frailty affected the types of concerns people were experiencing (See Table 7 below). There are slightly different proportions of the top ten concerns per frailty level, however, the same concerns appear in each of the frailty categories. Note the N values are different for the severe frailty category with less data provided for this group.

Mild Frailty N=685	**%**	**Moderate Frailty N=611**	**%**	**Severe Frailty N=199**	**%**
Mobility	12.8	Mobility	25.5	Mobility	15.6
Other physical problems/conditions	6.7	Managing the household/assistance with daily living	17.8	Housing	8.5
Managing the household/assistance with daily living	6.7	Pain/aches	11.7	Managing the household/assistance with daily living	8.0
Housing	6.4	Housing	8.5	Family and relationships	6.5
Continence	4.5	Family and relationships	8.0	Other physical problems/conditions	4.5
Pain/aches	4.4	Other physical problems/conditions	7.7	Pain/aches	4.0
Falls or balance issues	4.4	Falls or balance issues	7.2	Getting out	4.0
Family and relationships	3.5	Social interaction	6.4	Continence	3.5
Social interaction	3.1	Continence	5.6	Social interaction	3.5
Independence	2.8	Independence	4.2	Falls or balance issues	3.0

Table 7. Concerns split by mild, moderate and severe frailty

3.4 Analysis of MYCaW® concerns in each supercategory

In this section we report the breakdown of MYCaW® concern categories. Understanding the range of concerns that patients need support with demonstrated the large range of issues that staff are supporting.

3.4.1 Physical Concerns

41% of all MYCaW® concerns reported physical concerns. As shown in Figure 4 the top category was 'mobility' (37%) followed by 'Other physical problems/ conditions' (14%). Other physical problems referred to issues with range of conditions, e.g., cardiovascular disease, arthritis, cancer, oedema, skin problems. None of these conditions were frequent enough to comprise their own category hence being added into other physical problems and conditions.

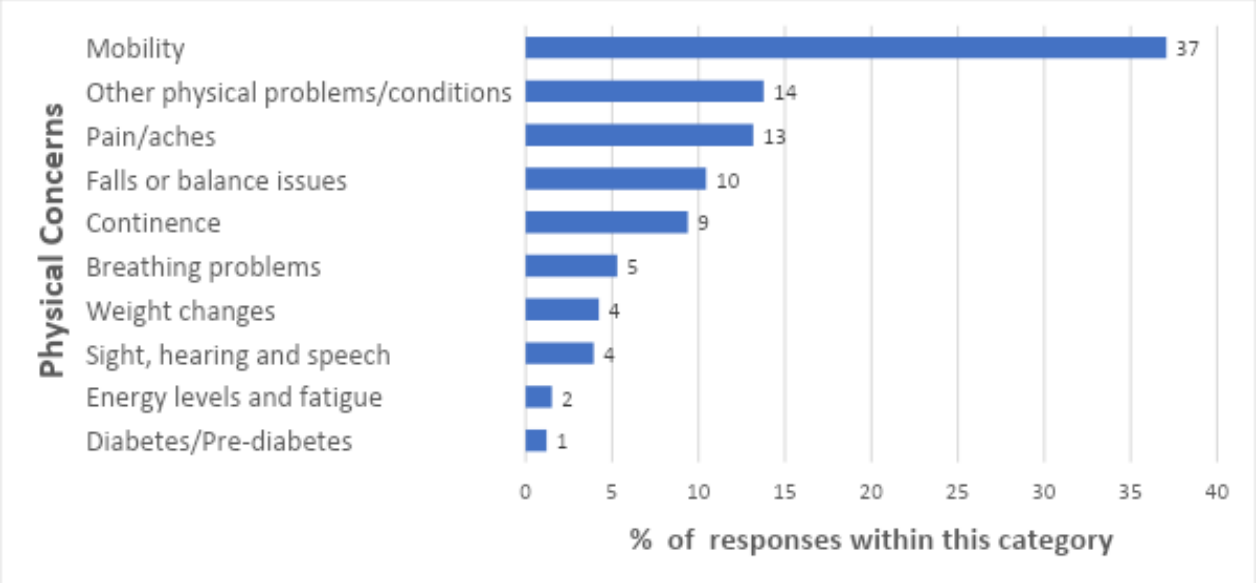


Figure 4. Analysis of the Physical MYCaW® concerns.

See Table 8 below for example quotes for each of these physical categories which portray examples from patients with different CFS(Rockwood) scores, ages and genders.

Category	Example Quotes	Demographics
Mobility	*"To be more mobile to be able to walk to the Prom"* *"My walking is not very good and I can't walk to the park anymore"*	CC@H, 85-89, Male, Rockwood 5 CC@H, 90-94, Female, Rockwood 6
Other physical problems/conditions	*"My biggest concern is the fluid in my leg and my wounds".* *"My itchy skin is what gets me down"*	CC@H, 75-79, Male, Rockwood 4 SCFS, 80-84, Male, Rockwood 5
Pain/aches	*"I would like something a bit stronger for my pain"* *"I have arthritis and my shoulders are very painful at the moment"*	CC@H 70-74, Male, Rockwood 6 CC@H, 80-84, Female, Rockwood 6
Falls or balance issues	*"I would like to be more steady on my feet"* *"Falls and poor balance - over 10 in the past year*	CC@H, 90-94, Male, Rockwood 5 SCFS, 90-94, Female, Rockwood 6
Continence	*"My incontinence throughout the night"* *"My waterworks and getting to the toilet in time. Suddenly need to go."*	SCFS, 85-89, Male, Rockwood 5 CC@H, 80-84, Female, Rockwood 6
Breathing problems	*"It is really scary when I get really breathless and have a coughing fit"* *"Breathlessness is my main concern and how I can manage myself it happens or gets worse"*	SCFS, 55-59, Male, Rockwood 6 SCFS, 85-89, Male, Rockwood 3
Weight changes	*"To lose weight"* *"Work on maintaining or gaining weight as much as possible"*	CC@H, 45-49, Male, Rockwood 5 SCFS, 85-89, Female, Rockwood 5
Sight, hearing and speech	*"I would like to get my hearing checked"* *"I hope my sight doesn't get any worse"*	CC@H, 80-84, Male, Rockwood 6 CC@H, 80-84, Male, Rockwood 3
Energy levels and fatigue	*"I haven't got any strength. I will go without food and drink as can't face getting up".* *"I am extremely tired most of the time, and stay in bed until around 3pm"*	CC@H, 95+, Female, Rockwood 6 CC@H, 80-84, Male, Rockwood 9
Diabetes/Pre-diabetes	*"I am having frequent hypo's my husband can't go out and leave me"* *"I would like some support around my diabetes management"*	CC@H, 80-84, Female, Rockwood 7 CC@H, 80-84, Female, Rockwood 5

Table 8. Example quotes for the different categories of physical concerns

3.4.2 Practical Concerns

19% of all concerns reported were in the practical supercategory. As shown in Figure 5, 'managing the household/ assistance with daily living' was the most frequent type of concern (45%). These concerns related to cooking, administration, paying bills, cleaning the house, bathing, getting dressed, needing assistance getting out of bed, and access to a cleaner or gardener.

The category called 'other practical concerns referred to a range of practical concerns beyond managing the household and activities of daily living. For example, these concerns could relate to arranging a funeral, applying for a blue badge, determining if there is wheelchair access at shops, as well as accessing appointments and services.

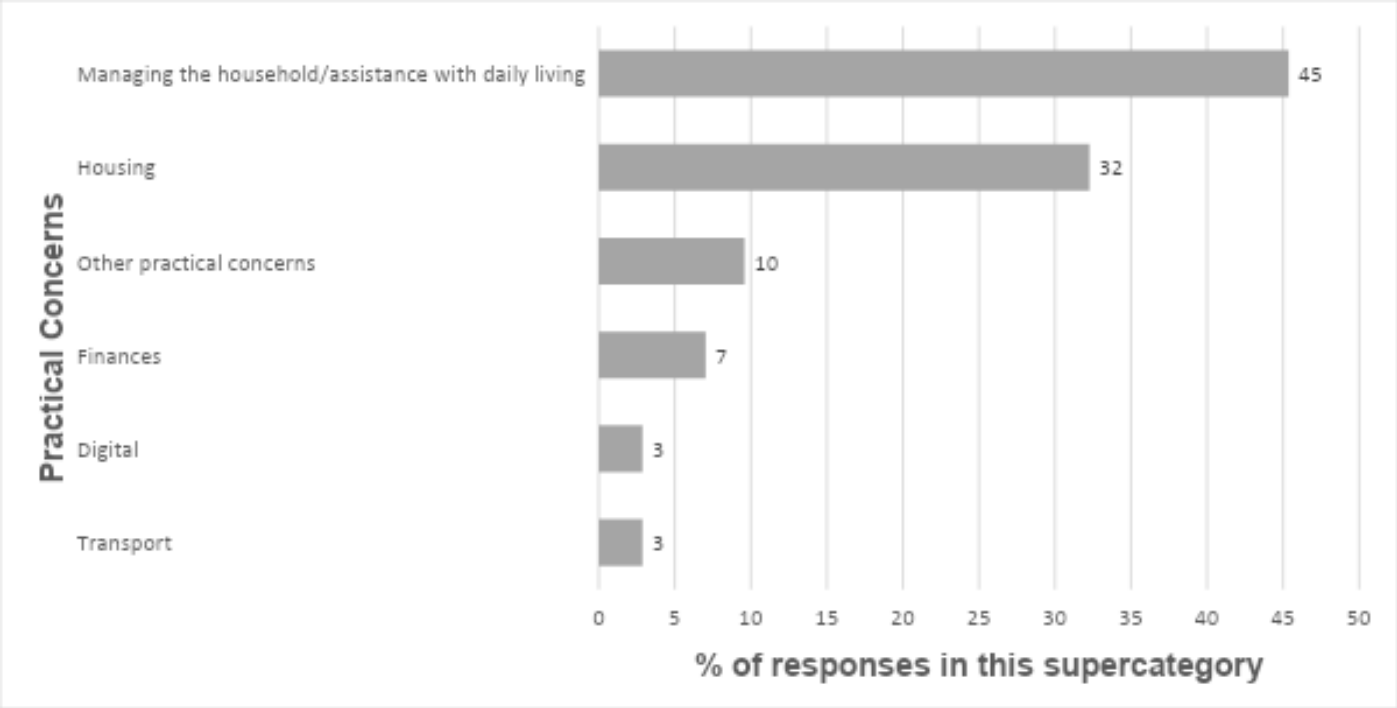


Figure 5. Analysis of Practical MYCaW® concerns supercategory

The concerns relating to housing were wide ranging and related to adaptations needing to be made in the home, concerns with selling or buying property and land issues. There were also concerns relating to the desire to remain at home, and concerns about moving home, as well as feeling safe at home.

For examples of people's practical concerns, refer to Table 9 below. These examples reflect a broad range of patient demographics.

Table 9. Examples of practical concerns reported by people living with frailty

Category	Example quote	Demographics
Managing the household/assistance with daily living	*"My house keeping- worried about keeping my house clean"* *"Difficulty managing showering, getting meals etc. Would like carer to visit daily and assist"*	CC@H, 70-74, Male, Rockwood 6 SCFS, 80-84, Female, Rockwood 4
Housing	*"Would like to have own space and not sleep on the sofa"* *"I want to move as I am too restricted/isolated in my current flat due to 2 flights of stairs which I cannot use"*	CC@H80-84, Female, Rockwood 6 SCFS, 60-64, Female, Rockwood 6
Other practical concerns	*"I would like a wheelchair so that my family can take me out."* *Help to support me to be sure what is planned and help me with structure in my life*	CC@H, 80-84, Female, Rockwood missing SCFS, 80-84, Female, Rockwood 5
Finances	*"My income and paying my pay is of most concern"* *"I don't want to run out of money"*	CC@H, 80-84, Male, Rockwood 6 SCFS, 95-99, Female, Rockwood 7
Transport	*"Transport from here. I can't drive anymore. It's difficult to get out from here."* *Getting from A to B*	CC@H, 80-84, Female, Rockwood 6 SCFS, 70-74, Male, Rockwood 5
Digital	*"To be able to use phone and order food to be delivered"* *'Technology'*	CC@H, 60-64, Female, Rockwood 5 CC@H, 85-89, Female, Rockwood 6

3.4.3 Mental and Emotional Concerns

Only 17% of all concerns were reported in this category – see Figure 6 below for the full breakdown of individual concerns. The top 2 concerns were relating to 'family and relationships' (26%), and concerns related to 'dementia, memory and confusion'.

'Family and relationships' included concerns with family members or relationships with family members. These concerns could, therefore, relate to the dynamics between a patient and their family carer and concerns about providing support and care for a family member. We also included any references to pets as family members in this category.

Many of the other categories are more obvious as to what they encompass. The category called 'The Future' related to concerns about the future in general and any care directives, e.g., wishes about resuscitation or staying out of hospital. Example quotes from each category is in Table 10, representing people of different ages, genders and frailty levels.

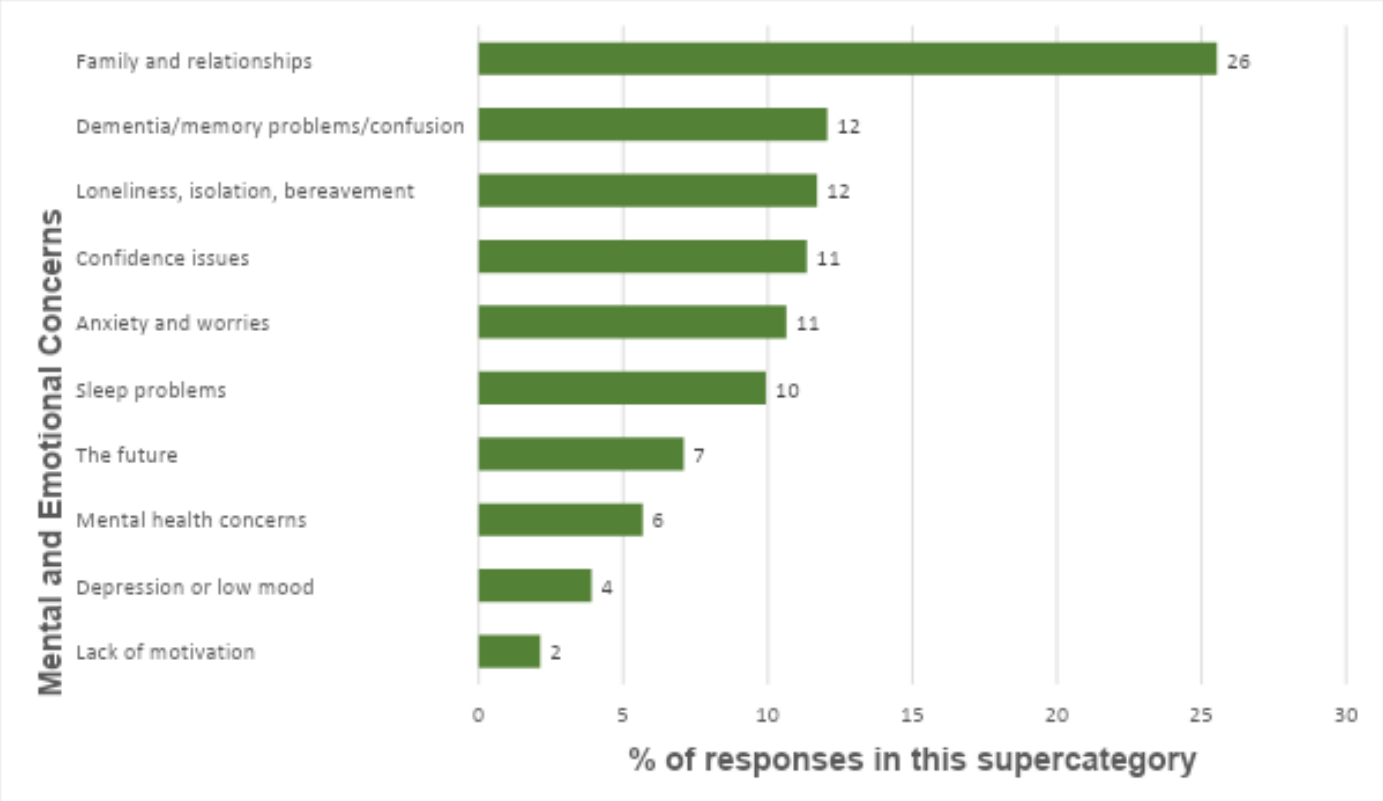


Figure 6. Analysis of Mental and Emotion MYCaW® concerns

Table 10. Examples of mental and emotional concerns reported by people living with frailty

Concern	Example quote	Demographics
Family and relationships	*"Husband and his Frustrations and anxiety"* *"Keeping my husband at home."*	85-89, Female, Rockwood 6 CC@H 90-94, Female, Rockwood 6
Dementia/memory problems/confusion	*"I am concerned that I may have the start of Dementia"* *"Mind is going"*	SCFS, 90-94, Female, Rockwood 5 CC@H, 85-89, Female, Rockwood 6
Loneliness, isolation, bereavement	*"Being alone, I like a bit of company - I get panic attacks"* *"Loneliness. I try to deal with it, but I'm isolated"*	SCFS,85-89, Female, Rockwood 6 CC@H, 85-89, Female, Rockwood 5
Anxiety and worries	*"I feel anxious about being alone and whether I am doing okay."* *"Worried about my forthcoming surgery"*	SCFS, 90-94, Female, Rockwood 6 CC@H, 85-89, Male, Rockwood 5
Confidence issues	*"Build up my confidence in going out"* *"My confidence for going out"*	CC@H, 80-84, Female, Rockwood 5 SCFS, 90-94, Male, Rockwood 3
Sleep problems	*"Sleep- how to stay awake"* *"I seem to sleep a lot"*	SCFS, 90-94, Male, Rockwood 6 CC@H, 95+, Female, Rockwood 4
The future	*"I would like me and xxxx to remain well in ourselves living at home"* *"To stay out of hospital - I don't like them, and I don't want to go again"*	CC@H, 75-79, Male, Rockwood 4 SCFS, 85-89, Female, Rockwood 5
Mental health concerns	*"Talking about my feelings and not crying"* *"Concerns with my mental health and want to be able to move forward and have counselling"*	SCFS), 70-74, Female, Rockwood 5 CC@H, 45-49, Male, Rockwood 4
Depression or low mood	*"Low mood in the morning"* *"My depression and the effect it has on my family"*	SCFS, 90-94, Female, Rockwood 6 CC@H, 80-84, Male, Rockwood 4
Lack of motivation	"I would like to feel more like going downstairs" *"I'm getting old and can't be bothered"*	CC@H, 90-94, Female, Rockwood 6 CC@H, 90-94, Female, Rockwood 8

3.4.4 General Health and Wellbeing concerns

General health and wellbeing accounted for 12% of the whole dataset and is broken down in Figure7 below. The most frequent concerns related to 'social interaction', where people specifically stated they wanted to, or had concerns about interacting with other people. The 'getting out' category specifically related to concerns about getting out of the house, going out more, the desire to get out or not being able to get out – these were concerns where social interaction may happen but was not explicitly mentioned. People that had concerns about their 'general health and wellbeing' were noticing a deterioration happening, wanted to take more time for themselves, or know how to improve their health and wellbeing.

The people who specifically mentioned 'physical activity or exercise' were put into a discrete category. These people had concerns about being more physically active, accessing more activity and exercise as well as not being sure what physical activity is safe for their circumstances.

Further example quotes for this supercategory can be found in Table 11.

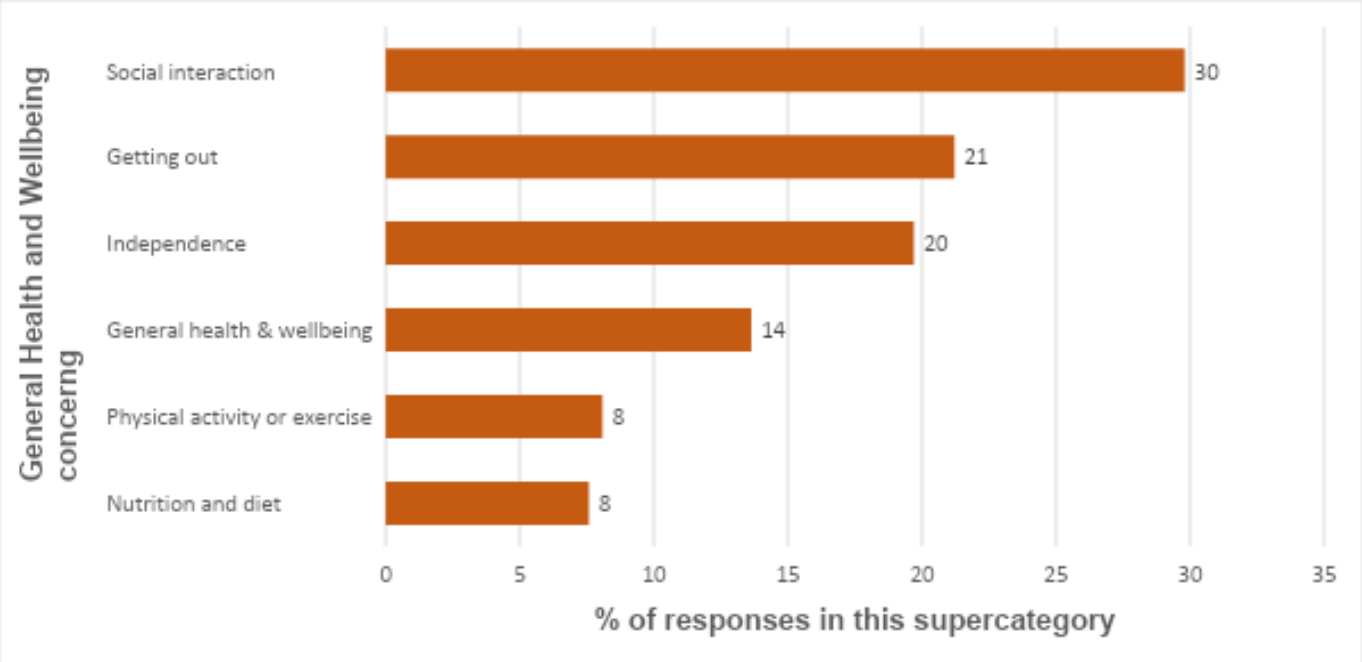


Figure 7. Analysis of General Health and Wellbeing MYCaW® concerns Supercategory

Table 11. Examples of concerns reported relating to people's general health and wellbeing

Category	Example quote	Demographics
Social interaction	*"I would like to get out more and meet other people"* *"I would like to get out to local church during the week to chat to people"*	CC@H, 85-89, Female, Rockwood 5 SCFS, 80-84, Female, Rockwood 7
Getting out	*"I would like to get out and walk with my dog again"* *"To be able to go out and stem the boredom and without pain"*	SCFS, 80-84, Female, Rockwood 5 CC@H, 75-79, Female, Rockwood 4
Independence	*"I want to maintain my independence and remain at home"* *"I have to rely on people especially my wife."*	CC@H90-94, Female, Rockwood 3 SCFS, 80-84, Male, Rockwood 7
General health & wellbeing	*"To live a good clean life and look after myself"* *"I'm not where I thought I would be in my recovery post stroke"*	CC@H, 90-94, Female, Rockwood 6 SCFS, 75-79, Male, Rockwood 5
Physical activity or exercise	*"Not being very active, I've always been an active person"* *"Getting fit and mobile again"*	CC@H, 100-104, Female, Rockwood 7 CC@H, 80-84, Male, Rockwood 6
Nutrition and diet	*"Not much of an appetite, I haven't got a desire to eat, no energy"* *"Weight monitoring and diet guidance"*	CC@, 60-64, Female, Rockwood 4 SCFS, 85-89, Female, Rockwood 5

3.4.5 Concerns about healthcare and service provision

Only 5% of concerns from the whole dataset fell into this supercategory, nevertheless these are important concerns (see Figure 8). Concerns about 'healthcare or social care provision' (31%) included the lack of support from healthcare providers, lack of communication between different healthcare providers and the need for advice relating to a medical issue.

The 'medication category' specifically identified concerns about why a medication was prescribed or the desire for a medication review to sort out their medicines due to unwanted side-effects.

People who reported concerns about accessing or wanting physiotherapy or who were concerns about their strength (or lack of it), where categorised in the 'physiotherapy and strength category'.

Finally concerns about' support and information' related to getting support and finding out specific information, availability of specific types of support and wanting to ask someone for advice or guidance. The services referred to could relate to counselling, complementary therapies, respite care, and online health and wellbeing sites.

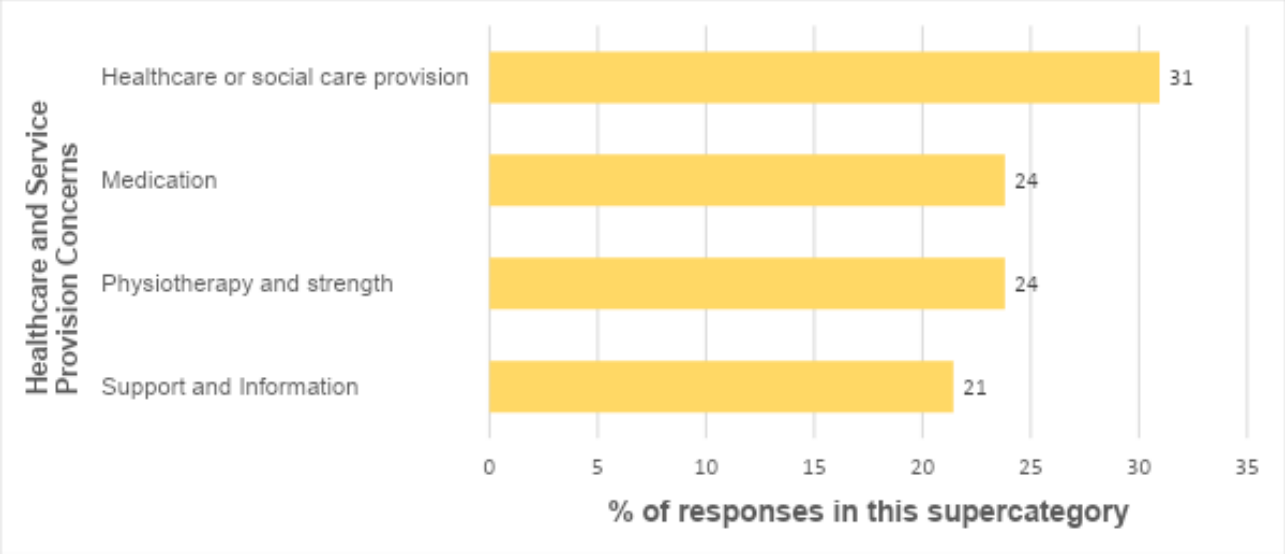


Figure 8. Analysis of MYCaW® concerns in the Healthcare and Service Provision

Table 12. Examples of concerns reported relating to people's Healthcare and Service Provision

Category	Example quote	Demographics
Healthcare or social care provision	*" I would like a hip replacement"* *"Home help due to my fractured arm."*	SCFS, 75-79, Female, Rockwood 6 CC@H, 90-94,Male, Rockwood 4
Physiotherapy and strength	*"I would like some physio for my right shoulder"* *"Help me gain my strength and balance"*	CC@H, 75-79, Female, Rockwood 5 SCFS, 85-89, Male, Rockwood 6
Medication	*"Making sure the medication I am taking is all that is needed"* *"Medication - ensuring I am taking the right medication at the right time"*	CC@H, 70-74, Male, Rockwood 5 SCFS, 90-94, Male, Rockwood 6
Support and Information	*"I need to know I can have a regular break to rest as I am caring for xxxxx"* *"Support with advance planning"*	CC@H, 90-94, Female, Rockwood 5 CC@H, 75-79, Female, Rockwood 4

3.5 Analysis of MYCaW® concerns and wellbeing scores

To understand how well the frailty services are supporting people's concerns that are identified using MYCaW®, the severity of concerns was scored at baseline and at follow-up. A total of 432 patients (45% of baseline sample), had paired baseline and follow-up MYCaW® concern and wellbeing scores data for analysis. Reasons for not obtaining follow up data include:

- 191/967 people passed away during the time following the baseline data collection,
- Some people may have deteriorated beyond the point of being able to collect follow up data,
- A proportion of the sample that only had chance to complete the baseline forms when the cut-off point occurred for sharing the evaluation data for analysis.

The overall score changes denoted that there are statistically significant improvements in the mean concerns and wellbeing scores for these people living with frailty (a negative score change denotes an improvement in the severity of concerns and wellbeing). Patients scoring a 1-point change or more are designated as reaching a minimal important difference. This can be positive or negative but denotes the level of change that is highly noticeable and clinically relevant.

MYCaW® Scores	Mean baseline score (SD)	Mean follow-up score (SD)	Score change and significance	% minimal important improvement	% minimal important deterioration
Concern 1 (n=432)	4.6 (+/-1.5)	2.9 (+/-1.9)	-1.7 (p<0.001)	68%	9%
Concern 2 (n=366)	3.4 (+/-2.4)	2.2 (+/-2.1)	-1.0 (p<0.001)	42%	6%
Wellbeing (n=420)	3.1 (+/-1.7)	2.6 (+/-1.6)	-0.4 (p<0.001)	46%	20%
Profile (n=419)	3.7 (+/-1.4)	2.6 (+/-1.4)	-1.1 (p<0.001)	68%	9%

Table 13. Summary of MYCaW® score changes (n=432). *A profile score is the mean of concerns 1, concerns 2 and the wellbeing score. If there is no concern 2, then it is the mean of the scores for concern 1 and wellbeing only. A negative score change denotes and improvement in the severity of concerns or an improvement in wellbeing. Patients scoring a 1-point score change or more are designated as reaching a minimal important difference. This can be positive or negative but denotes the level of change that is highly noticeable and clinically relevant*.

When looking at the percentage of people who reached a minimal important difference, 68% of patients had a minimal important improvement in their main concern and 67% in their level of wellbeing, which is a very good result considering that many of the sample population have a modal age of over 85-89 years old.

Nine percent of patients had a minimal important deterioration in their main concern and 20% met this threshold level of deterioration in their wellbeing. Reasons for why deteriorations in wellbeing may have occurred will be explored in the following sections, but first we analysed whether changes in concerns and wellbeing scores were affected by the level of frailty a person was living with.

3.6 Does the severity of the CFS (Rockwood) score affect MYCaW® concerns or wellbeing?

Interestingly, there was no correlation between the level of score change for MYCaW® concern or wellbeing and a person's CFS (Rockwood) score. This may be because there are a lower proportion of people with CFS (Rockwood) that fall in the severe category (n=47) for the statistical analysis to pick up a true trend. The mean score in the severe frailty category was 7.2 (+/-0.6) It is likely that there would need to be at least twice as many data points in this category for the correlation analysis to identify a potential correlation here, hence repeating this analysis at a future point is recommended. Despite the low numbers of people with follow up scores in the severe frailty category, some trends can be identified as explained below.

When the MYCaW® scores were analysed as mean changes per frailty category where scores were designated as either mild frailty (1-5), moderate frailty (6) or severe frailty (7+), there were some trends and changes in levels of score changes – see Table 14.

- Statistically significant improvements in score changes for concerns were detected for every category of frailty severity. Therefore, irrespective of the type of concern or level of frailty, MYCaW® concern scores are significantly improving.

- The level of concern and wellbeing score changes, is nearly identical in the mild and moderate frailty categories. Similarly, the percentage of people who reach a minimal important threshold in score changes is also very similar in the mild and moderate frailty categories.

- For people in the severely frail category, the level of score change for their main concerns matches those in the mild and moderate categories. The mean wellbeing score changes, however, are much lower and not statistically significant.

- There is a discrete decrease in the proportion of people who have a minimal important increase in score changes and a reciprocal increase in the proportion of people who have a minimal important deterioration in concern and wellbeing scores when comparing across mild, moderate and severe frailty categories. To ascertain if this is a true reflection of trends, more data from people living with severe frailty needs to be collected and analysed – ideally at reaching n=100.

Rockwood category	MYCaW® Scores	Mean baseline score (SD)	Mean follow-up score (SD)	Score change (significance)	% minimal important improvement	% minimal important deterioration
Mild (1-5) mean score 4.5 SD (+/-0.7)	Concern 1 (n=200)	4.6 (1.6)	3.0 (1.9)	-1.6 (p<0.001)	68%	9%
	Concern 2 (n=171)	3.3 (2.4)	2.0 (2.0)	-1.1 (p<0.001)	45%	6%
	Wellbeing (n=197)	3.1 (1.7)	2.5 (1.6)	-0.5 (p<0.001)	49%	19%
	Profile (n=196)	3.6 (1.4)	2.6 (1.5)	-1.0 (p<0.001)	68%	8%
Moderate (6) mean score 6.0 SD(+/-0)	Concern 1 (n=159)	4.5 (1.6)	2.7 (2.0)	-1.7 (p<0.001)	68%	10%
	Concern 2 (n=135)	3.5 (2.3)	2.3 (2.1)	-1.0 (p<0.001)	44%	6%
	Wellbeing (n=155)	3.0 (1.7)	2.6 (1.6)	-0.4 (p<0.01)	44%	21%
	Profile (n=50)	3.5 (1.5)	2.6 (1.4)	-0.9 (p<0.001)	68%	10%
Severe (7+) mean score 7.2 SD(+/-0.6)	Concern 1 (n=47)	4.9 (1.1)	3.3 (1.7)	-1.5 (p<0.001)	62%	16.%
	Concern 2 (n=34)	4.0 (2.1)	3.2 (2.0)	-0.6 (p<0.05)	32%	8%
	Wellbeing (n=45)	2.8 (1.9)	2.9 (1.6)	+0.02 (p=NS)	38%	24%
	Profile (n=44)	3.8 (1.6)	3.2 (1.3)	-0.6 (p<0.01)	61%	16%

Table 14. MYCaW® scores split by the CFS (Rockwood) categories of severity

3.7 What other things are affecting people's health?

On the follow-up MYCaW® form, it is optional for people to state if there is anything else going on in their life that they feel is important. Typically, people only respond with information about major situations in their life. Changes in wellbeing can be due to many issues that are not related to the service provision that is being evaluated. Determining what else is happening in a person's life can, therefore, provide more insight into the data analysis. The data for this question is summarised below.

- 184/432 people at follow-up provided data and 204 different data items were reported.
- Overall, 57% were positive category type responses, 43% were negative type responses.

Type of impact	Categories	% (n=184)
Positive impact	Positive support from health or social care professionals	17
	Positive change to existing health	11
	Positive impact on general wellbeing	11
	Improvement in level of independence	6
	Increased support	6
	Positive change to housing set up	5
Negative impact	Negative change to existing health	24
	Negative impact on general wellbeing	10
	Decreased support	4
	Bereavement	3
	Issues experienced with health and social care professionals	1
	Negative change to housing set up	1

Table 15. Overall frequencies of categories in the "What other things are affecting people's health?" question

Reviewing the data in table 15, it is interesting to note that nearly a quarter of the respondents reported a negative impact in their existing health condition. This helps to explain why some wellbeing scores did not improve and in fact deteriorated.

Also, to note that 17% of the respondents have a positive impact from health or social care professionals. This related to getting onward assessments and referrals set up or having attended appointments for additional support need. Frequently the needs of the patient had been established by the frailty matrons, who were then responsible for getting the additional appointments set up. For the patients, this was felt to be a very positive outcome of the support they received. Example quotes for each of the categories can be found in table 16 below.

3.7.1 Other things going on in your life split by frailty category

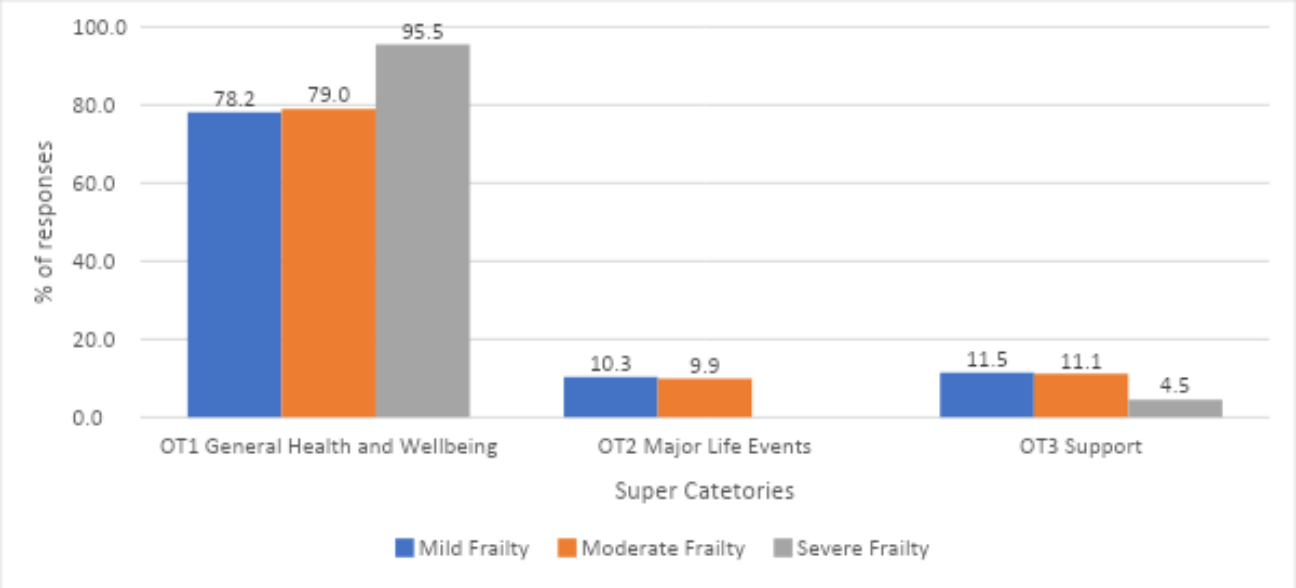


Figure 9. The order of the frequency of "Other things going on in your life?" stratified by CFS (Rockwood) (Mild n=77, Moderate n=69, Severe n= 24).

Figure 9 shows that people living with mild and moderate frailty show the same patterns of scores, however, people living with severe frailty show higher frequency of responses in the 'General Health and Wellbeing category'. This group also shows less in Support and none in "Major life events". It is important to collect more data from patients, especially those living with severe frailty before drawing firm conclusions from this data.

Table 16. Example quotes of positive 'other things' that were happening in people's lives.

Category – positive changes	Example quote	Demographics
Positive support from health or social care professionals	*"I have had regular podiatry which in turn has helped my walking - I get my corns looked at regularly"* *"I have found the perching stool has been of great beneficial has helped me have a wash"*	SCFS, 85-89, Male, Rockwood 7 CC@H, 80-84, Male, Rockwood4
Positive change to existing health	*"Started anti-depressant and also had injections into shoulders"* *"Bowels - I now feel more in control, it's going along more regularly now."*	SCFS, 80-84, Male, Rockwood 6 CC@H, 75-79, Female, Rockwood 7
Positive impact on general wellbeing	*"I have returned to dancing"* *"I have improved in communication, I am walking regularly with outreach worker and socialising at friendship café"*	SCFS, 85-89, Male, Rockwood 4 CC@H, 70-74, Male, Rockwood 4
Improvement in level of independence	*"May privately source a mobility scooter in the future to support getting out into the community more"*	CC@H, 75-79, Male, Rockwood 6
Increased support	*"I have supportive neighbours"* *"Still have problems with my legs but I manage. Now have carers coming in and assisting and will go out with daughter on scooter."*	SCFS, 95-99, Female, Rockwood 6 CC@H. 70-74, Male, Rockwood 6
Positive change to housing set up	*"I have moved into a ground floor flat so now it is easier to get out in my wheelchair, and my walking has improved with my 4WW inside"* *"Moving into Sheltered housing has been really positive move. I'm enjoying the social activities here and making new friends".*	SCFS, 90-94, Female, Rockwood 6 CC@H, 75-79, Female, Rockwood 5

Table 16 continued. Example quotes of other things happening in people's lives

Category – Negative changes	Example quote	Demographics
Negative change to existing health	*"I have had covid and a long hospital stay, I now need hoisting all of the time"* *"My vision has deteriorated. I have to go to the ophthalmic department in 3 months. I have macular degeneration starting. I get double vision at times."*	SCFS, 85-89, Female, Rockwood 7 CC@H, 95+, Male, Rockwood 7
Negative impact on general wellbeing	*"Just getting older and bones creaking"* *"I have now accepted that I can't engage in activities as before. I am very slow these days and have good days and bad days. Therefore, I am not keen on gardening and social activities these days."*	SCFS, 85-89, Female, Rockwood 5 CC@H 85-89, Female, Rockwood 6
Decreased support	*"Husband [carer] had a heart attack so I went into care home for 8 weeks respite"* *"I'm down - my husband died suddenly at beginning of pandemic - I will never get over this. He used to help with shower and around house. My memory - I forget. He used to do the work. It gets to me."*	SCFS, 90-94, Female, Rockwood 8 CC@H, 75-79, Female, Rockwood 6
Bereavement	*"Wife passed away a few weeks ago quite suddenly"* *"Loss of son and dog diagnosed with further health conditions"*	SCFS, 90-94, Male, Rockwood 6 CC@H, 60-64, Female, Rockwood 5
Issues experienced with health and social care professionals	*"Concerns with care provider, call times constantly changing, not sleeping in bed as bedtime call too early"*	CC@H, 45-49, Female, Rockwood 7
Negative change to housing set up	*"Washing facilities are difficult- having to wash my hair in the sink as I am waiting to hear about funding to have a stairlift fitted so I can access my bathroom."*	SCFS, 80-84, Female, Rockwood 6

3.8 Patient experience of the service – what was most important?

The final follow-up question on MYCaW® asks what a person found most important about the service or support they received. 351/432 people responded to this question. Responses were categorised and are displayed in Figure 10 below.

The most frequent response (20%) related to the support, understanding and provided by the staff in the frailty services as well as the encouragement to make changes or improvements. Patients also appreciated that other members of the family were involved in the conversations with the frailty staff.

"I feel as if you're the only person I can come to for help, you're a lifeline really" SCFS, 100-104, Female, Rockwood 7

"It's your loyalty to us, someone's on our side". CC@H, 85-85, Male, Rockwood 5

The second largest category (16%) identified how patients felt genuinely listened to and felt the staff were interested in what was important to the patient. Many patients in this category also appreciated the face-to-face setting.

"That you take the time to listen and are understanding. It's lovely to know the team are there if I need them" SCFS, 80-84, Female, Rockwood, 6

"The company - I've enjoyed having you visit. (daughter) became tearful at this point and said how important it has been for us supporting her" CC@H, 90-94, Male, Rockwood 6

Twelve percent of patients reported that the most important thing about the service was becoming more mobile, sociable or independent as a result of the support they received.

"You have helped me to realise the importance of staying active and focusing on the positives on what I am managing to do." SCFS, 85-89, Male, Rockwood 5

"Improving my state of mind and my feeling of wellbeing. I have gradually been gaining more independence." CC@H, 75-79, Female, Rockwood 5

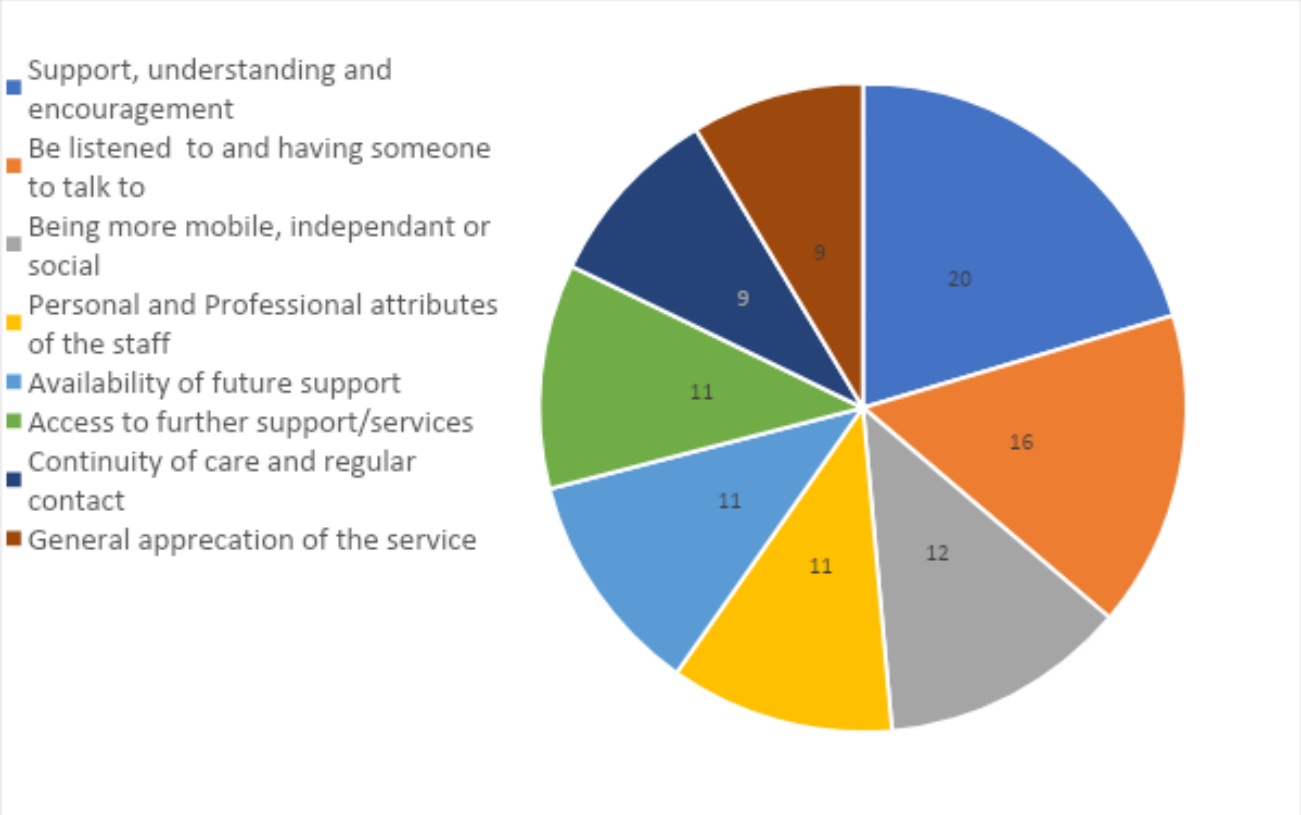


Figure 10. Percentage responses for people in response to "What was the most important thing about the service?"

As well as being listened to, patients (11%) reported how cheerful, kind and caring the frailty staff were, providing high quality of information, clinical support, answering questions and providing assistance with equipment.

"That (Staff member) is always there, and I love her visits. She has helped me with my anxiety and breathing" SCFS 95-99, Female, Rockwood 6

"You are lovely cheerful people, I can build a rapport with you" CC@H, 95+, Male, Rockwood 7

Access to support was very important to patients and there were 2 dimensions to the responses analysed. Eleven percent of patients really appreciated knowing that there is someone there for them and who to contact if they need support in future.

"Knowing there is somebody there, if I need them" SCFS, 85-89, Female, Rockwood 5

"Having someone who I could call if we were worried" CC@H, 85-89, Female, Rockwood 6

The other dimension that patients appreciated (11%) was the help from the frailty nurses to get their wider support needs met, e.g., housing, benefits, equipment and other appointments.

"Getting the extra support in place" SCFS, 85-89, Female, Rockwood 6

"Having the carers arranged for me, helping with bathing, dressing and applying cream. Also changing my pad" CC@H, 90-94, Female, Rockwood 7

Continuity of care and regular contact by the frailty nurses was highlighted by 9% of respondents. The continuity and regular contact bring reassurance to the patient, knowing that someone is looking out for them and they are not forgotten.

"Knowing that xxx checks on us regular and knowing that she is there should we need her for anything" SCFS, 75-79, Female, Rockwood 5

"Having regular visit and support at home so I am able to be more independent again" CC@H, 95+, Female, Rockwood 5

Finally, 9% of people made general appreciative comments about the frailty service for example, *"Everyone from Complex care has been first class"* CC@H, 65-69, Female, Rockwood 5

To understand if the severity of frailty influenced what people found most important about the service, the data was categorised as per Figure 11. The numbers of responses are much lower in the severe frailty category, (mild (n=140), moderate (n=145), and severe (n= 47) frailty).

Figure 11 shows that there is a difference between frailty levels and frequencies of what was most important about the service. Caution should be given when interpreting this figure due to low numbers of people in each category, but it does appear that people living with severe frailty most value the staff contact and having someone alongside them.

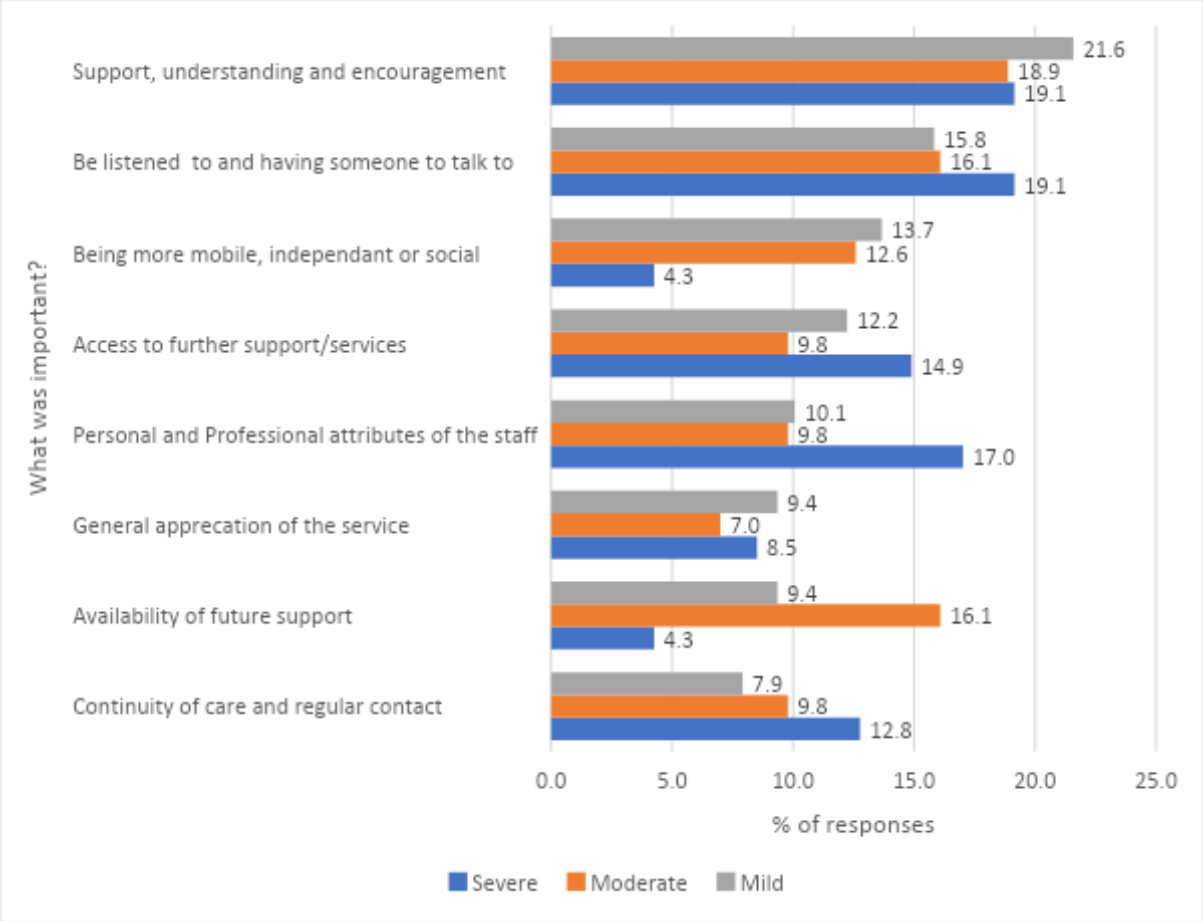


Figure 11. shows the order of the frequency of "What was most important about the service?" stratified by CFS (Rockwood) scores.

3.9 Staff experience of using MYCaW®

Nineteen responses to the anonymous survey sent to staff using MYCaW® were obtained from a range of professionals including community matrons, health and wellbeing coordinators, occupational therapists, physiotherapists, service leads and an IT training manager (see Appendix F for questions used). Due to anonymous completion, there may have been a small amount of duplication of staff responses from 2021 and 2023. 16/19 professionals stated that there were no issues using MYCaW®**,** that it was a positive experience, as the tool was simple to use, fitted their work and patient needs, and helped to keep their discussion with their patient focussed.

"It's very simple to use" Community Matron

"I have found it very useful as a focus on what we are trying to achieve with and for the patient. It will bring a drifting situation back to our original assessment objectives and goals." Community Matron

Other professionals noted how MYCaW® enabled them to understand what is most important to their patient and gather feedback from them.

"Really good conversation starter and enables the service to gather rich data and feedback on patient and service outcomes" Service Lead

"Keeps focus for the patient – professional relationship – working together for what is most important to the patient" Health and Wellbeing Coordinator

"It captures a snapshot of what is or is not working for the patient." Occupational Therapist

Three people highlighted practical implementation issues around how the MYCaW® data is inputted or uploaded onto the digital system, but not with the tool itself.

3.9.1 Improving accessibility of MYCaW®

Collecting data outcomes from people with dementia was noted by the community matrons to be challenging at times. A guidance document on how to manage this process was co-produced by

Meaningful Measures Ltd, the commissioner and the community matrons, to ensure everyone was following an agreed procedure. The guidance highlighted when to move to using a proxy person to complete MYCaW® (e.g., a carer), or when collecting any form of outcome data was not appropriate. A pictorial scale was also developed to accompany the numerical MYCaW® scale to aid patients when rating their concerns and wellbeing. This development built on a similar pictorial scale that piloted for a sister tool to Measure Yourself Medical Outcomes Profile® (MYMOP®) in 2004. The community matrons trialled the pictorial scale, found that it improved the ability of people to rate their concerns and wellbeing and continue to use it.

4.0 Discussion

4.1 Identifying the needs of people who are living with frailty

As the number of people over 85 years old in the population will almost double by 2045, it is now a priority to identify and support the needs of people living with frailty. Whilst our understanding of frailty has progressed, there remains disagreement on the conceptualisation of frailty amongst healthcare practitioners and how frailty is identified[19,20, 21.] Many outcomes that matter to older people living with frailty are not routinely collected by the NHS[22], yet if frailty can be slowed or even reversed with the right prevention and care are provided, this could lead to improvements in quality-of-life and financial savings for health systems.

Locally, Gloucestershire Integrated Care System (ICS) has developed a number of strategies and transformation programmes which inform personalised proactive models of working with people living with frailty. The ICS Frailty Strategy (2022-2027)[23] focuses on improving resilience, reducing the risk and impact of frailty and the Ageing Well Programme. This is underpinned by a 'One Gloucestershire' strategic approach to embedding personalisation in practice.

This evaluation report represents the second phase of work implementing the MYCaW® questionnaire into Gloucestershire ICS frailty services. This report has explored the acceptability of MYCaW® as a core monitoring tool in the personalised frailty services to demonstrate the impact of the services and more fully understand what patients living with frailty want support with. The data will enable the ICS to determine how well the personalised services are meeting the ICS Frailty Strategy priorities.

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[19] Hollinghurst J, Housley G, Watkins A, Clegg A, Gilbert T, Conroy SP. A comparison of two national frailty scoring systems. Age Ageing. 2021 Jun 28;50(4):1208–14.

[20] Alharbi K, van Marwijk H, Reeves D, Blakeman T. Identification and management of frailty in English primary care: a qualitative study of national policy. BJGP Open. 2020 Apr;4(1):bjgpopen20X101019.

[21] Sanderson J, Kay N, Watts R. Universal Personalised Care: The Implementing the Comprehensive Model [Internet]. 2019. Available from: https://www.england.nhs.uk/personalisedcare/

[22] Khan N, Randhawa G, Hewson D. Integrated Care for Older People with Different Frailty Levels: A Qualitative Study of Local Implementation of a National Policy in Luton, England. Int J Integr Care. 2023 Mar 23;23:15.

[23] https://glostext.gloucestershire.gov.uk/documents/s84881/Item%209%20-%20Appendix%201%20Frailty%20Strategy.pdf

4.2 Acceptability and accessibility of using MYCaW® in a population living with frailty

Feedback from the anonymous survey to practitioners using MYCaW® with people living with frailty highlighted how useful MYCaW® was in opening up conversations, understanding what was important to a person, and providing rich, relevant personalised data. The tool enabled a systematic approach to opening "What Matters to Me" conversations. It also provided valuable insights into the extent to which services positively impacted the outcomes for individuals and more broadly the cohorts of people they are working with. This evidence is very helpful in establishing the value and benefits of the frailty services. This feedback echoes the view of Conroy and Van Oppen[8], who also recognised the value of shared decision making and asking what matters to the patient. Allowing people to designate whatever concerns are at the front of their mind, fits with the World Health Organisation (WHO) strategy of meaningful engagement [24]. This strategy, amongst other things, calls for individuals with lived experience of chronic conditions to have bi-directional engagement in their conversations with health professionals, and a redistribution of power to enable equal decision-making processes to occur.

It has been noted in previous research[25, 26] that collecting outcome measures data from some people with dementia often fails to mirror meaningful outcomes for people with dementia. It is noticeable that the outcomes mentioned that are often missing for people living with frailty[8] or dementia[26,27] are captured using MYCaW®**.** This makes the MYCaW® tool a meaningful approach to understanding a person's concerns, thus supporting the awareness, knowledge and understanding of frailty and supporting personalised care planning and coproduction.

4.3 Increasing the accessibility of MYCaW®

To increase the accessibility of MYCaW®, particularly for patients who found it harder to rate their concerns and wellbeing using a score, a pictorial scale was developed to accompany the numerical rating scales. Pictorial scales are widely used as alternatives or adjuncts to written

[24] World Health Organisation. WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions. 2023.
[25] Clarke C, Woods B, Moniz-Cook E, Mountain G, Øksnebjerg L, Chattat R, et al. Measuring the well-being of people with dementia: a conceptual scoping review. Health Qual Life Outcomes. 2020 Dec 24;18(1):249.
[26] Øksnebjerg L, Diaz-Ponce A, Gove D, Moniz-Cook E, Mountain G, Chattat R, et al. Towards capturing meaningful outcomes for people with dementia in psychosocial intervention research: A pan-European consultation. Health Expectations. 2018 Dec;21(6):1056–65.

items on outcomes measures (e.g.,[27,28]). After piloting by the community nurses with patients, the addition of the pictorial scale was found to improve the accessibility of MYCaW® and people's ability to rate their concerns and wellbeing.

Community matrons also noted that some patients living with frailty and diagnosed dementia felt they had no concerns, despite their carer or the frailty matron recognising that they needed support. A team decision was taken, therefore, to only attempt to collect MYCaW® data where the person felt able to say what their concerns were. On a few occasions a loved one or carer stated what they thought the concern was, acting as a proxy. There is no way of knowing how accurate this was for the patient. This situation is discussed further by Burks et al. (2021)[29] who seeks to understand what influences the proxy person when completing outcomes measures and how this may or may not be reflective of the experience of the person living with dementia. There is therefore a category on the frailty coding framework to identify which people were unable to generate concerns.

4.4 Creating a standardised framework of MYCaW® concerns for people living with frailty

This evaluation has reported the first set of MYCaW® concerns and development of a framework, using data from people living with frailty as a dedicated sample population. Because MYCaW® allows a person to nominate their primary concerns, this allows them to talk about issues that are relevant to them. This might be a medical condition or situation they are being supported for, or other pressing concerns associated with determinants (e.g., housing, working, finances, digital issues). Whatever the concerns may be, if these are their most pressing concerns then they will likely to be detrimentally affecting their wellbeing. As such these concerns should be supported as a priority.

The first version of the MYCaW® frailty framework was developed in 2020/21, in Phase 2 of this work. The framework has been updated in this Phase 2 project with a larger dataset (1,625 concerns from 967 people) and further independent testing via collaboration with the researchers

[27] Baxter AL, Watcha MF, Baxter WV, Leong T, Wyatt MM. Development and Validation of a Pictorial Nausea Rating Scale for Children. Pediatrics. 2011 Jun 1;127(6):e1542–9.

[28] Noll E, De Angelis V, Bopp C, Chauvin C, Talon I, Bennett-Guerrero E, et al. Pictorial adaptation of the quality of recovery 15 scale and psychometric validation into a pediatric surgical population. Sci Rep. 2023 Aug 28;13(1):14085.

[29] Burks HB, des Bordes JKA, Chadha R, Holmes HM, Rianon NJ. Quality of Life Assessment in Older Adults with Dementia: A Systematic Review. Dement Geriatr Cogn Disord. 2021;50(2):103–10.

in Health Innovation Wessex. The final framework was from Phase 2 has now been submitted for peer reviewed publication (ref paper to be published).

The MYCaW® frailty framework identified 36 concern categories split into five themes: Mental and Emotional Concerns; Physical Concerns; Healthcare and Service Provision Concerns; Concerns about General Health and Wellbeing; Practical Concerns. Whilst comparing this framework of concerns to other similar outcome measures recommended in this population, it was noted how some aspects affecting a person have not been reported yet. For example, whilst the Long-Term Conditions questionnaire items broadly picked up most of the concerns people living with frailty identified, concerns relating to finances, transport and digital are missing. Furthermore, these are all health inequalities that need supporting in this population but cannot be if they are not first identified.

The top scoring concern overall was "Mobility" with 15% of all concerns for the whole sample relating to this issue. Mobility was also the top concern regardless of frailty level. The other most frequent concerns related to managing the household/assistance with daily living, other physical conditions, housing concerns and pains & aches. It is noticeable that 2 of these concerns are not directly health related but relate to wider social needs. A review by Van Oppen et al. (2022) [30] suggest four potential PROMS (COOP/Wonca charts, EuroQoL, McGill QoL expanded and Palliative care outcome scale), that could be used with older people who have frailty, in an emergency setting. None of these recommended measures had items that were representative of the breadth of outcomes that were important to people, when compared to this MYCaW® frailty framework. To differing degrees, items associated with practical issues and health inequities with digital, transport, housing, and financial concerns were the most often missing from these pre-itemised outcome measures. In a policy environment where addressing what matters to a person[8,31] and decreasing the impact of health inequities are priorities at a local[24], national [22, 32,

[30] van Oppen JD, Alshibani A, Coats TJ, Graham B, Holch P, Lalseta J, et al. A systematic review and recommendations for prom instruments for older people with frailty in emergency care. J Patient Rep Outcomes. 2022 Dec 1;6(1):30.

[31] NHS. The NHS Long Term Plan [Internet]. 2019. Available from: www.longtermplan.nhs.uk

[32] HM Government. Levelling Up the United Kingdom [Internet]. 2022 [cited 2023 Sep 8]. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1052706/Levelling_Up_WP_HRES.pdf

[33] and global level[25], there is an urgent need for outcome measures to collect this type of personalised data.

4.5 What impact are the frailty services having for people living with frailty?

Statistically significant improvements in the mean score changes were with the 432 patients with follow-up data. This demonstrates that people's mains concerns and problems are being met by the personalised frailty services and that overall, this is having a positive impact on patient's wellbeing. 68% of patients had a minimal important improvement in their main concern and 67% in their level of wellbeing. As is to be expected, a smaller percentage or people did not have an improvement in their concerns (9%) and wellbeing (20%) scores.

When split by frailty level, statistically significant improvements in mean score changes for concerns and wellbeing were detected for people living with mild and moderate frailty. For people living with severe frailty the mean score changes for the concerns were statistically significantly improved, but mean wellbeing score changes were not. At Meaningful Measures we advise that confidence in statistical analysis can be reached with approximately 100 paired data sets, hence there is not yet enough follow up data for people living with severe frailty to determine the impact of the frailty service on their wellbeing.

Data from the follow-up MYCaW® explored if there were other things happening in people's lives that were affecting their health. Of the 184/432 people who provided data, 57% were positive category type responses, 43.1% were negative type responses. For instance, 24% of people had a negative related to their health in the window of time they were providing MYCaW® data and 17% of respondents reported a positive impact from health or social care professionals. The change in MYCaW® scores, therefore, cannot be fully attributed to the frailty service provision when there are other confounders at play. Previous research has shown that the level of score changes can be significantly affected by other things happening in people's lives, although there was not statistical significance in this dataset[34]. To fully understand how much change is attributable to the frailty services, a control group of data would be required.

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[33] Marmot M, Allen J, Goldblatt P, Boyce T, McNeish D, Grady M, et al. Fair Society, Healthy Lives: The Marmot Review [Internet]. 2010 [cited 2023 Sep 8]. Available from: https://www.parliament.uk/globalassets/documents/fair-society-healthy-lives-full-report.pdf

[34] Polley MJ, Jolliffe R, Boxell E, Zollman C, Jackson S, Seers H. Using a Whole Person Approach to Support People with Cancer: A Longitudinal, Mixed-Methods Service Evaluation. Integr Cancer Ther. 2016 Dec;15(4):435-445. https://doi.org/10.1177/1534735416632060

Lastly, the follow-up MYCaW® also asked people to identify what had been most important about the frailty service. 351 people responded to this question and the most frequent response (20%) related to the support and understanding provided by the staff in the frailty services as well as the encouragement to make changes or improvements. People also felt genuinely listened to, appreciated a face-to-face setting and reported that the service helped some of them become more mobile, sociable or independent as a result of the support they received. Collecting this data demonstrates why personalised services are an important approach and how they are widely valued by the service users, in particular highlighting that how the frailty service has impacted a person in a way that may slow down or reverse their frailty situation, which would likely reduce health services usage in the long term.

4.5 Limitations of this work

There are several limitations in this project. The number of patients with follow up data only represented just over half of all eligible patients at baseline. 18% of patients passed away, which is to be expected when the modal age was 80-85 years old. Additional health service pressures were created due to the impact of the Covid-19 pandemic on older people and it was not aways felt ethically appropriate to collect MYCaW® data. Finally, there were some people who provided baseline only data when the analysis cut-off date occurred. It is also notable that less data was collected from people living with severely frailty, and this may have been due to staff working in more adverse and extreme circumstances.

In addition, it should be noted that there is no control group of equivalent people who were living with frailty who did not receive these services to compare the sample to. Also, the sample may not represent other populations, as the demographic is mostly white, female and local to Gloucestershire. The findings and patterns in the qualitative coding framework may only be relevant to this population, therefore it would be interesting to have the framework used in other frailty contexts.

5.0 Conclusion

This current report shows that MYCaW® is acceptable, and useful in terms of collecting person-centred outcome data relevant to people living with frailty. MYCaW® has been successfully piloted as a core monitoring tool for use with people living with frailty by Gloucestershire Clinical Commissioning group (now Gloucestershire Integrated Care Board). Data showed statistically significant improvements in people's concerns and wellbeing scores. Clinical and operational staff found the MYCaW® tool was simple to use, fitted their work and patient's needs, and helped to keep their discussion with their patient focussed.

The new coding framework of MYCaW® concerns specific to frailty, has been robustly tested and refined within this population and can now be applied to other projects with similar patients elsewhere in the world. The coding framework is useful as it allows personalised data to be systematically collected which other outcome measures with pre-determined lists of answers cannot collect and ultimately it allows the voices of people living with frailty to be heard, particularly when concerns relate to social determinants of health. In a policy environment where addressing what matters to a person and decreasing the impact of health inequities are priorities at a local, national and global level, MYCaW® is a tool that enables a meaningful approach to understanding a person's concerns, supports personalised care planning, coproduction and identification of inequalities.

6.0 Recommendations

There are several key recommendations that have come out of this work which are detailed below:

1. **There is ongoing MYCaW® usage:** MYCaW® is a key method of establishing the outcomes a service is achieving with a specific cohort of people within Gloucestershire ICS. MYCaW® data should be continued to be collected to benchmark service's performance, and monitor the key concerns of the population it serves. More data in each level of frailty severity should be collected and coded against the MYCaW® coding framework as standard practice on a yearly basis. Note, if current systems are still a logistical barrier, then other digital versions of MYCaW® do now exist and can be explored. Further exploration into what may improve the collection of follow-up data is also recommended.

2. **Using MYCaW® data to inform service development:** Top concerns generated should be contrasted against current policy and spend decisions within service provision to ensure the optimum services are available to meet the needs of people living with different levels of frailty. Furthermore, this data can be used to identify potential training needs for staff.

3. **Reasons for not completing MYCaW® to be documented systematically:** Initial and follow-up MYCaW® data was not possible to collect on several occasions. It would be useful to build into the system a way to record why MYCaW® data could not be collected. One simple way of doing this is to enter the reason in the first concern box of the tool. This data could be investigated to determine under what circumstances the data is not able to be collected. It may be that those living with the most severe frailty cannot provide responses to MYCaW®, and if so, proxies should be used to provide this data, and if not possible this should be recorded on the form.

4. **Pictorial scale to be further tested:** An innovation from this project was to create the pictorial scale with smiley faces to accompany the number Likert scale for MYCaW®. Further testing of the understanding, validity and acceptability of this extra tool should be carried out. People living with frailty should be asked their opinions of pictorial tool.

7.0 Appendices

Appendix A: Clinical Frailty Scale (Rockwood)

Community services currency guidance: frailty and last year of life NHSE doc states that mild/ moderate and severe frailty on Rockwood are classified as follows:

- **Mildly frail (score of 5 or less)**
- **Moderately frail (score of 6)**
- **Severely frail (score of 7 or more)**

Clinical Frailty Scale*

1 **Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

2 **Well** – People who have **no active disease symptoms** but are less fit than category 1. Often, they exercise or are very **active occasionally**, e.g. seasonally.

3 **Managing Well** – People whose **medical problems are well controlled,** but are **not regularly active** beyond routine walking.

4 **Vulnerable** – While **not dependent** on others for daily help, often **symptoms limit activities.** A common complaint is being "slowed up", and/or being tired during the day.

5 **Mildly Frail** – These people often have **more evident slowing,** and need help in **high order IADLs** (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

6 **Moderately Frail** – People need help with **all outside activities** and with **keeping house**. Inside, they often have problems with stairs and need **help with bathing** and might need minimal assistance (cuing, standby) with dressing.

7 **Severely Frail** – **Completely dependent for personal care**, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~ 6 months).

8 **Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

9. **Terminally Ill** - Approaching the end of life. This category applies to people with **a life expectancy <6 months**, who are **not otherwise evidently frail.**

Scoring frailty in people with dementia

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

* 1. Canadian Study on Health & Aging, Revised 2008.
2. K. Rockwood et al. A global clinical measure of fitness and frailty in elderly people. CMAJ 2005;173:489-495.

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Appendix B: Guidance developed by Gloucestershire services in collaboration with Meaningful Measures Ltd regarding how to implement the MYCaW® tool with people living with frailty

Guidance for staff working with older or vulnerable people

MYCaW® concerns should be elicited at the appropriate time in the first session with a person. There is no fixed point for this.

- We recommend that you carry out wider holistic needs and general conversation about a person's situation and wellbeing, and then near to the end of a session try to introduce the MYCaW® question on concerns and problems.
- This can serve as a way of prioritising what action needs to be taken. It may take a little discussion to find the priorities.
- You may scribe for a person, please keep their words in the first person when you write down the concerns.

When working with older people, not everyone is willing/capable of providing answers to questionnaires on their own. This could be due to cognitive impairment for instance.

- Please use your professional judgement at this stage as to whether you feel it would be better to fill in the form on someone's behalf. As trained professionals you will know if this is the case.
- You may see the person with their carer present in which case the carer may want to complete MYCaW® on the persons behalf.
- Any proxy responses from carer or staff are still important to collect, but, if possible, it is always preferable to obtain the responses directly from the person themselves.
- It is important to tick the relevant box on the page of the tool to show who has filled in the form.

Sometimes it is not appropriate to collect questionnaire data from a person.

- There are ethical boundaries on collecting data and a person may be too agitated or anxious and by collecting data on a questionnaire this may feel inappropriate to the conversation that is taking place. Whilst MYCaW® is a very 'consultation-friendly' questionnaire, there may still be times when it isn't appropriate.
- A person has the right to refuse to provide answers.
- A person may not be capable of understanding the questions and there may not be another person to complete the questionnaire.
- Meaningful Measures Ltd respects your professional judgement in these situations.
- It is good practice to record why MYCaW® was not completed, so it doesn't look as if it was missed out. Please add a note in the concerns box and/ or top sheet if this happens.

Any other questions please contact hello@meaningfulmeasures.co.uk

Appendix C: Consent form

One Gloucestershire
Transforming Care, Transforming Communities

NHS
Gloucestershire Health and Care
NHS Foundation Trust

Measure Yourself Concerns and Wellbeing (MYCaW®)

First MYCaW® Date:		**Second MYCaW® Date:**	

	Face-to-face	**Telephone**	**Video Consultation**
Method of delivery: Please tick relevant box			

	Person	**Carer on behalf of person e.g. family**	**Staff member on behalf of person**
Completed by: Please tick relevant box **Please include staff member's name below:**			

IMPORTANT INFORMATION

The South Cotswolds Frailty Service, Complex Care at Home Service and the Clinical Commissioning Group in Gloucestershire are doing some work with the people who have developed the MYCaW® questionnaire, their company is called Meaningful Measures Ltd.

Together we are trying to better understand the types of concerns that people have; and understand how we can best work with people to help them address their needs. We are aiming to help Gloucestershire CCG to provide the best frailty service it can.

Throughout the process your identity will be hidden and will not be accessible to the researchers though they will have access to your, age, gender, ethnicity and first three letters of your postcode.

I consent to my anonymised data being shared with Meaningful Measures Ltd

☐ Yes

☐ No

If you have any queries about this questionnaire please speak to your matron or wellbeing coordinator. You can contact any member of the team on: 0300 421 1389 or 0300 421 6367.

Thank you for your help. Yours sincerely, Complex Care at Home Team

Appendix D: Supplementary Table 1. Evolution of MYCaW® coding framework, from original integrative oncology framework to frailty framework

This table documents why concern categories from the original coding framework were either removed, amended to broaden their inclusion criteria, amalgamated into other existing categories, or where new categories to reflect frailty related concerns were added in.

Super-category	Original categories (2007/2015)	Final Frailty Categories (2023)
S1 - Psychological and Emotional Concerns Changed to Mental and Emotional Concerns as mental health is now a more commonly used term.	"Adapting and coping"	**Removed - not mentioned**
	"Body image concerns"	**Removed - not mentioned**
	"Confidence issues"	"Confidence issues"
	"Depression/low mood"	"Depression/low mood"
	"Emotional problems"	*Developed - reworded to "Mental Health concerns"*
	"Family and relationships"	*Developed - included concerns between carers and patients, family relationships in general and pets as family members*
	"Fear and anxiety"	*Amended - to "Anxiety and Worries" as mentions of fear were not present in this data set. Many more concerns relating to worries were present instead.*
	"Psychological issues"	*Amalgamated - into the mental health category*
	"Regaining balance and normality"	*Amalgamated - now reflected in practical concerns category on work.*
	"Sleep problems"	"Sleep problems"
	"Stress and tension"	**Removed - not mentioned**
	"Support"	**Removed - support features in other categories in a different context, therefore overlap of term avoided**
	"The future"	"The future"
	-	**New – "Loneliness, isolation and bereavement"**
	-	**New – "Dementia/memory problems/confusion"**
	-	**New – "Lack of motivation"**
S2 - Physical Concerns	"Hot flushes and night sweats"	**Removed - not mentioned**
	"Fertility"	**Removed - not mentioned**

	"Pains/aches"	"Pain/aches"
	"Physical problems not related to cancer"	*Reworded - minor change to "Other physical problems/conditions"*
	"Poor energy levels"	*Reworded - minor change to "Poor energy levels or fatigue"*
	"Cancer recurrence"	**Removed - not mentioned/ cancer specific**
	"Spreading of cancer"	**Removed - not mentioned/cancer specific**
	"Weight change"	"Weight change"
	-	**New – "Diabetes/pre-diabetes"**
	-	**New – "Continence"**
	-	**New – "Sight and hearing"**
	-	**New – "Mobility"**
	-	**New – "Developed further into Falls and balance issues"**
	-	**New – "Breathing problems"**
S3 Hospital Cancer Treatment Concerns - Whole supercategory removed as cancer specific	"Cancer treatment in general" "Side effects of chemotherapy" "Side effects of hormonal treatment" "Side effects of surgery" "Side effects of radiotherapy"	**Whole super-category removed as cancer specific**
S3 - Healthcare and service provision concerns - New supercategory developed	-	**New – "Support and information"**
	-	**New – "Healthcare and social care provision"**
	-	**New – "Physiotherapy and strength"**
	-	**New – "Medication"**
S4 - Concerns about Wellbeing	"Exercise/Physical activity"	"Physical activity or exercise"
	"General wellbeing"	*Developed* - into "General health and wellbeing"
	"Healing"	**Removed - not mentioned**
	"Information and guidance on Complementary therapies"	**Removed - not mentioned**
	"Nutrition and diet"	"Nutrition and diet"
	"Relaxation"	**Removed - not mentioned**
	"Spiritual wellbeing - meaning and peace"	**Removed - not mentioned**
	"Spiritual wellbeing – faith"	**Removed - not mentioned**
	-	**New – "Getting out"**

	-	**New – "Independence"**
	-	**New – "Social interaction"**
S5 - Practical Concerns	"Finances"	"Finances"
	"Work"	*Amalgamated* - into "other practical concerns" below in context of getting back to normal activities (majority of this population are retired)
	-	**New – "Housing"**
	-	**New – "Managing the household/assistance with daily living"**
	-	**New – "Transport"**
	-	**New – "Other practical concerns"**
	-	**New – "Digital"**
T6 Statements that can't be coded - New supercategory added in	-	**New - Statements that can't be coded - this was added in to enable the statements lacking context, missing concerns etc to be identified.**

Appendix E: Final frailty framework

Theme	Code	Category
T1- Mental and Emotional Concerns Includes concerns relating to psychological and emotional issues. It excludes physical concerns.	T1a	Confidence issues
	T1b	Depression or low mood
	T1c	Mental health concerns
	T1d	Anxiety and worries
	T1e	Sleep problems
	T1f	Family and relationships
	T1g	The future
	T1h	Loneliness, isolation and bereavement
	T1i	Dementia/memory problems/confusion
	T1j	Lack of motivation
T2- Physical Concerns Includes concerns relating to physical aspects of a person.	T2a	Diabetes or prediabetes
	T2b	Pains or aches
	T2c	Other physical problems or concerns
	T2d	Energy levels or fatigue
	T2e	Weight changes
	T2f	Continence
	T2g	Sight and hearing
	T2h	Mobility
	T2i	Falls or balance issues
	T2j	Breathing problems
T3-Healthcare and service	T3a	Support and information

provision concerns Includes concerns relating to healthcare, support and external services.	T3b	Healthcare or social care provision
	T3c	Physiotherapy and strength
	T3d	Medication
T4-Concerns about General Health and Wellbeing Includes concerns about wider issues around living well and regaining or maintaining one's wellbeing.	T4a	Physical activity or exercise
	T4b	General health and wellbeing
	T4c	Nutrition and diet
	T4d	Getting out
	T4e	Independence
	T4f	Social interaction
T5-Practical concerns Includes data about non-health related concerns.	T5a	Finances
	T5b	Housing
	T5c	Managing the household / assistance with daily activities of living
	T5d	Transport
	T5e	Other practical concerns
	T5f	Digital
T6- Concerns that can't be coded	T6	Use this code when: ● Concerns not completed due to issues with dementia, cognition or a person's loss of ability to generate a concern for themselves. ● 'Declined' or 'none' written down ● Concerns without enough context to code ● Items written as update not as a concern

Appendix F: Staff feedback from using the tool

Staff Feedback questions regarding the use of MYCaW® Staff either using the tool in clinical practice or administrating the tool managing the data processing, store and reporting within their organisation were asked the following questions.

1. Were there any issues with collecting data using MYCaW®? (practical data collection issues, wording, instances it didn't work)

2. Were there any issues with embedding the MYCaW® data collection in your digital systems? (eg. EMIS/ SystmOne? Or any other systems you use)

3. Were there any issues with creating or using templates for MYCaW® in your digital systems?

4. Were there any issues with creating reports for MYCaW® data to output to Meaningful Measures Ltd?

5. What was the overall experience of using the MYCaW® tool in your work? (Does the tool fit your work needs, patient needs?).

REPORT END