

# Implementation of the MYCaW<sup>®</sup> questionnaire

A project commissioned by NHS England  
and NHS Improvement South West  
Integrated Personalised Care team

February 2022

Dr Helen Seers, Dr Nicole Collaço and Dr Marie Polley



Meaningful  
Measures



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**Disclaimer:** The views expressed in this report are those of the authors and do not represent those of NHS England and NHS Improvement South West Integrated Personalised Care programme.

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**Main contact:** Dr Helen Seers: [helen@meaningfulmeasures.co.uk](mailto:helen@meaningfulmeasures.co.uk) (Co-Director, Meaningful Measures)  
Meaningful Measures (Company Number 12800470).

#### **About the authors:**

**Dr Marie Polley BSc, PhD, PgCert HE, Reiki Master** Marie is Co-Founder and Co-Director of Meaningful Measures and Visiting Reader at University of East London. Marie is a biomedical scientist and has a PhD in molecular biology of how cancer develops. Marie has worked in measuring the impact of holistic or person-centred approaches to supporting health and wellbeing. Recently Marie co-founded the Social Prescribing Network, which has led a social movement around the use of non-medical activities to support people's wider determinants of health and provide additional routes of support to traditional pharmaceutical prescribing. Social Prescribing has now been adopted by the NHS in England and is being taken up internationally. Marie led the team to write the first national guidance for social prescribing and continues to be a thought leader and strategic advisor in this field, as well as working more broadly in the health and wellbeing sector.

**Dr Nicole Collaço, BSc (Hons), PhD, Research Fellow, and subcontractor to Meaningful Measures** Nicole is a research fellow in the Macmillan Survivorship Research Group (MSRG) at the University of Southampton and has a PhD in cancer survivorship - specifically focused on the experiences and needs of younger couples affected by prostate cancer. Nicole has extensive experience in qualitative research and has also worked on numerous mixed-methods studies. These studies include research on supporting men with prostate cancer and their partners, understanding how people use supportive services and resources to help self-manage consequences of cancer and its treatment, developing a nutritional awareness tool for use in remote paediatric consultations, and assessing the needs of children and young people with a serious condition and their parents during the Covid-19 outbreak. Nicole is also part of the evaluations programme for the MSRG, which is delivering a suite of evaluations on personalised care service innovation.

**Dr Helen Seers, BSc, PhD, CPsychol, Co-Founder, Co-Director Meaningful Measures Ltd, Visiting Research Fellow UWE** Helen is an experimental psychologist by training, and for the past 20 years has worked with voluntary, community and social enterprise organisations, supporting them to understand and communicate the impact of their work. Helen specifically understands the operating environment that many small organisations are facing, and the value that well-designed evaluations can bring to these organisations. As Head of Research and Evaluation at the integrative cancer charity Penny Brohn UK (2004-2019), Helen led a team of researchers who innovated a mixed-methods evaluation evidence base. This led to the publication of many academic papers evidencing the impact of the charity's work on patients. Since 2019, Helen has purely been a freelance research consultant working in collaboration with Dr Marie Polley on social prescribing projects.

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## Summary of development of the implementation of MYCaW®

Processes and guidance on how to implement and use MYCaW® for this pilot was developed by the CC@H and SCFS teams in collaboration with Meaningful Measures Ltd. This work represents collaborative and creative working between all stakeholders between Summer 2020 to present. A great deal of learning and sharing of ideas has taken place to enable the implementation of MYCaW® data collection for this pilot project. A separate complementary report detailing the results from the MYCaW® frailty pilot project accompanies this document. The following document is a repository of all the processes and development which enabled the project. A timeline is also included to show the stages of development and accompanying documents to the timeline are then attached.

### **The stages of development:**

#### **Development of data collection process**

To enable development, during the pilot project there was a monthly meeting between the clinical teams, management, and members of Meaningful Measures. These meetings enabled the implementation of MYCaW® data collection for this project. In addition, three training sessions on the practical use of MYCaW® data collection were held with staff who would be using this tool with their patients. This training allowed people to test procedures and ensure that data could be consistently collected. Meaningful Measures staff also learned from the practitioners in terms of issues with collecting data from a frail population.

From these meetings and the training, a set of guidance notes on how to collect data with the MYCaW® tool with people living with frailty was generated. These guidance notes covered scenarios where it was not appropriate to collect data, and how to ensure data was collected which captured the patient's voice. Staff were advised to record responses that were verbatim in terms of the responses from patients, and not summarise concerns to one word, or a broad issue (e.g., lonely). Guidance was also given in terms of instances when it was appropriate for members of staff to capture the concerns of patients who may not have been able to determine these (due to extreme frailty or dementia) – these instances of data collection relied on clinical judgement on the part of the practitioner and were used as a last resort.

#### **Development of digital data capture processes**

During the project work and meetings, the Business Intelligence staff within the CC@H and SCFS teams, in partnership with Meaningful Measures were also able to develop their approach to digital systems capturing the MYCaW® data and producing reports.

SystemOne and EMIS were programmed by expert staff to display the MYCaW® tool and enable effective data capture. A template was created for EMIS and SystemOne using temporary codes for the MYCaW® tool's questions. The template was engineered to allow data capture from the first time MYCaW® to be piped through to be available to be shown at the point of follow-up. Reporting to create an excel file of data for analysis by Meaningful Measures from the EMIS and SystemOne templates was a challenging task for the teams. There was a great deal of learning and development which has been internally shared.

#### **Development of data security processes**

A robust DPIA was carried out with all partners to ensure a high standard of data security. Data was cleaned by the business intelligence team to remove any identifiers (names/ locations). Care was taken to ensure data transmission was done in a secure way (via password protected Excel file sent to a secure NHSE email address held by Meaningful Measures). Meaningful Measures also ensured compliance with the DSPT (Data Security Protection Toolkit) to enable appropriate processes in terms of digital security, storage and management of data.

## Implementation timeline

**July 2020** SWIPC identified MYCaW® as a potentially useful tool for use within its personalised care frailty services. Initial meeting held to explore common ground with Meaningful Measures. Tool identified as useful and innovative, and agreement with funding from SWIPC/ NHSE&I put in place to take forward the project.

**August 2020** Monthly project meetings initiated to enable the implementation of the MYCaW® tool within the pilot project. Meaningful Measures MYCaW® licence issued to CC@H and SCFS and data share part of licence back to Meaningful Measures agreed. Meaningful Measures Data Share and licence policy details can be found here: [Data-share-of-MYCaW®-and-MYMOP-with-Meaningful-Measures.pdf \(d35b2zkvr8496.cloudfront.net\)](https://d35b2zkvr8496.cloudfront.net/measure-yourself-tool-license-policy.pdf)  
<https://d35b2zkvr8496.cloudfront.net/measure-yourself-tool-license-policy.pdf>

**August 2020** Meaningful Measures and the business intelligence teams meet to determine how MYCaW® can be embedded within EMIS and SystemOne. Temporary codes in templates are used to create these versions of the tool for this pilot project. (See document 1 for screen shots of digital templates). Functionality of online data collection determined and fidelity check carried out on the MYCaW® tool displayed to ensure that the tool was not altered or invalidated by digital presentation adapted from the original paper format.

**September 2020** Meaningful Measures achieve compliance with the NHSE Data Security Protection Toolkit standards to enable best practice working with NHSE data. Meaningful Measure also granted an NHSE email address to be able to receive data safely.

**September 2020** Meaningful Measures staff provided training to clinical teams regarding the concept behind the MYCaW® tool, and how it can be used in clinical practice to collect data. (See document 2 for screenshots of training). Feedback obtained from staff in terms of technical issues with data collection.

**September 2020** Co-produced consent form bespoke for project was produced jointly by the CC@H and SCFS teams – allowing patients to be informed by staff of the purpose of collecting the data and providing the option to opt out. (See document 3 for details of recruitment of people to the pilot project and 4 for consent form and MYCaW® tool itself). Co-produced guidance for working with vulnerable groups developed jointly with the CC@H and SCFS teams. (See document 5 for guidance). Telephone script for administering the MYCaW® tool consistently was developed by Meaningful Measures. (See document 6 for telephone script).

**October 2020** Flow chart of MYCaW® data collection process developed by CC@H and SSCFS (combined paper forms/ photograph of images and then digital input by administrator processes defined). (See document 7 for flow chart).

**October 2020** Dummy data in excel file report shown to Meaningful Measures to check if the CC@H service's data collection and reporting output of MYCaW® achieved the required data columns needed for analysis. Data contains agreed non-identifiable demographics and Rockwood score. DPIA drafted for project. (See document 8 for summary of DPIA). SOP for MYCaW® on processing data and sending to Meaningful Measure for data transfer created Document 9.

**November 2020** Data collection began using the consent form and tool live with patients in CC@H and SCFS. Data was collected by clinician or wellbeing coordinator recording responses into the clinical system via a MYCaW® template.

**November 2020 to September 2021** Monthly meetings continue to ensure project progress, data collection carries on by staff within community services and primary care.

**October/ November 2021** Data harvested from the digital systems for CC@H and SCFS and reports created to generate data in format to be transmitted to Meaningful Measures via secure email (nhs.net) to a nhs.net email address. The data is reviewed to ensure no identifiable patient data is provided to Meaningful Measures.

**November 2021** Analysis of data from the project begins

**February 2022** Deliverables of report, coding framework and implementation record created by Meaningful Measures

# Document 1 - screen shots of digital templates generated in EMIS and SystmOne for MYCaW® input

## MYCaW® Template design– EMIS

### MYCaW® Front Sheet

**Measure Yourself Concerns and Wellbeing MYCaW New v0.4**

Pages <<

- MYCaW Front Sheet
- MYCaW First Form
- MYCaW Follow up Form

**Measure Yourself Concerns and Wellbeing (MYCaW)**

First MYCaW date 17-Dec-2020 24-Sep-2020 >>

Second MYCaW date 17-Dec-2020 03-Dec-2020 >>

Method of delivery [dropdown] 03-Dec-2020 Consultation ... >>

MYCaW information gathered during discussion with: [dropdown] 03-Dec-2020 Discussed wi... >>

Text [input]

**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.

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 [dropdown] 03-Dec-2020 Consent give... >>

I consent to my anonymised data being shared with Meaningful Measures [dropdown] 03-Dec-2020 Consent give... >>

17-Dec-2020 [calendar icon]

Text [input]

If you have any queries about this questionnaire please speak to your Community Matron or Wellbeing Coordinator. You can contact any member of the team through your GP practice.

Thank you for your help.

Yours sincerely,

**South Cotswolds Frailty Service**

### Read Codes used

#### First MYCaW® Date

Term	Concept ID	Description ID
<b>Initial patient assessment</b>	315639002	460158010

**Second MYCaW® Date** – code under review at present. Had used “Follow up” but this is already in use by practices. Looking for an alternative code.

#### Method of delivery:

Term	Concept ID	Description ID
<b>Face to face consultation</b>	1672851000006100	1672851000006116
<b>Telephone consultation</b>	386472008	1480625018
<b>Consultation via video conference</b>	325921000000107	600851000000117

**MYCaW® information gathered in discussion with:**

Term	Concept ID	Description ID
<b>Discussed with patient</b>	395085009	1488784010
<b>Discussed with healthcare professional</b>	915451000000107	2351941000000118
<b>Discussed with carer</b>	395084008	1488783016

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

**YES**

Consent given to share patient data with specified third party

←

Clinical Terms (SNOMED CT), Release v168	<i>EMIS code</i> (navigational concept)
	Concept ID: 192931000006108
	Description ID: 192931000006112

**NO**

Declined consent for access to patient data for research purpose

*EMIS code*

←
→

Clinical Terms (SNOMED CT), Release v168	<i>EMIS code</i> (navigational concept)
	Concept ID: 192931000006108
	Description ID: 192931000006112

## MYCaW® Template design– SystemOne

### MYCAW

1 Is this an initial or follow up assessment?

Initial

Follow up



Please write down one or two concerns or problems which you would most like us to help you with

2 **Concern or problem 1 (if this is a follow up, use the lightning bolt to pull through the previous answer)**

Owing money to the Council



3 **Concern or problem 2 (if this is a follow up, use the lightning bolt to pull through the previous answer)**

Fear of falling



Please select a number to show how severe each of those concerns or problems is now. (0 Not bothering me at all - 6 bothers me greatly). This should be YOUR opinion, no-one else's!

4 **Concern or problem 1:**

0

1

2

3

4

5

6



Document 2 - Example screenshots of Meaningful Measures training slides



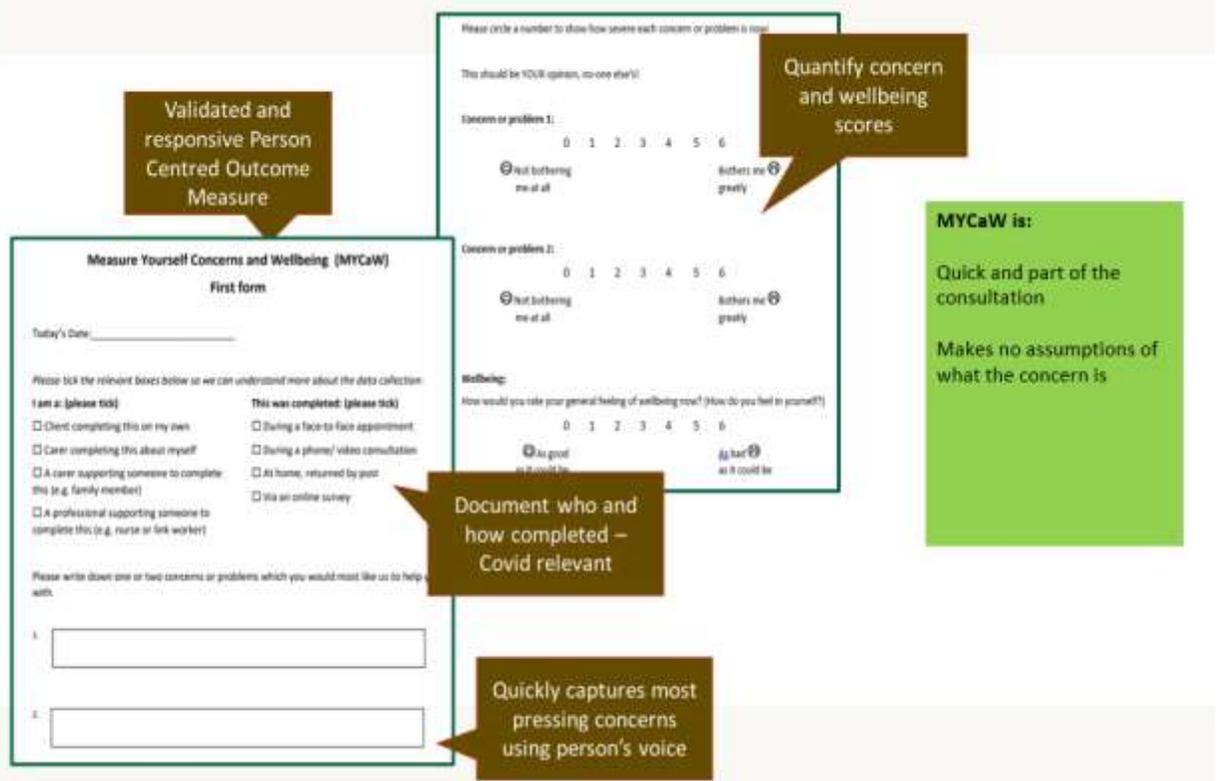
## Background to MYCaW

### Measure Yourself Concerns and Wellbeing

MYCaW was created in 2006 by Dr Charlotte Paterson – GP and researcher at University of Bristol.



MYCaW is sister of MYMOP – Measure Yourself Medical Outcomes Profile

**Validated and responsive Person Centred Outcome Measure**

**Quantify concern and wellbeing scores**

**MYCaW is:**  
Quick and part of the consultation  
Makes no assumptions of what the concern is

**Document who and how completed – Covid relevant**

**Quickly captures most pressing concerns using person's voice**

**Measure Yourself Concerns and Wellbeing (MYCaW) First form**

Today's Date: \_\_\_\_\_

Please tick the relevant boxes below so we can understand more about the data collection:

**I am a: (please tick)**

- I am completing this on my own
- A carer completing this about myself
- A carer supporting someone to complete this (e.g. family member)
- A professional supporting someone to complete this (e.g. nurse or link worker)

**This was completed: (please tick)**

- During a face-to-face appointment
- During a phone/ video consultation
- At home, returned by post
- Via an online survey

Please write down one or two concerns or problems which you would most like us to help with.

1.

2.

Please circle a number to show how severe each concern or problem is now. This should be YOUR opinion, no-one else's!

Concern or problem 1: 0 1 2 3 4 5 6

Not bothering me at all  Bothers me greatly

Concern or problem 2: 0 1 2 3 4 5 6

Not bothering me at all  Bothers me greatly

**Wellbeing:**

How would you rate your general feeling of wellbeing now? (How do you feel in yourself?)

0 1 2 3 4 5 6

As good as could be  As bad as it could be

## Document 3 - detail on people recruited into pilot study

Participants were recruited into this project by their use of the CC@H and SCFS services. All people within these services with a Rockwood Clinical Frailty Score generated were eligible to participate (with the following inclusion criteria).

### Inclusion criteria

- Adults living in the community living with frailty who are under the care of frailty services across a variety of settings – specifically Complex Care @ Home, the South Cotswolds Frailty Service, Frailty Nurses/Matron in primary care. (People who were eligible for a Rockwood scale assessment).
- Services working with adults with frailty in the community, ideally working in a personalised way e.g., using health coaching and personalised care and support planning.

### Exclusion criteria

- People living in care homes
- People under the age of 18
- Anyone who was not classed as mildly frail or worse on the Rockwood scale

Participation was optional and text at the top of the questionnaire was shown and/or read to all people who were eligible to provide their data for this project. People were given the chance to opt out of the project at this point and not provide their data. See document 4 for the full text which mentioned that unidentifiable, GDPR compliant anonymised data (age band, gender, ethnicity and first three letters of postcode) would be shared with Meaningful Measures.

### Data collection procedure

Rockwood data was collected in terms of the initial assessment point in accessing the service. Baseline MYCaW® data was collected by community matrons or link workers at the first session with the patient. At this point however, clinical judgement was made in terms of either omitting the data collection or postponing it to a second or later session if a patient was not able to engage, or if it was not possible during a session – see document 5 for the guidance notes in terms of discretion advice when collection this data.

Follow-up data collection occurred approximately three months after the first data collection. This window of time between first and second data capture was determined by the teams on the project, a consistent window of follow-up was applied as much as possible but there could be two or three weeks plus or minus this time point as leeway. Discretion was applied if follow-up data collection was not appropriate. It is noted that some people passed away before follow-up was carried out

### Data collection process by Complex Care at Home Service (CC@H) provided by Gloucestershire Health and Care Foundation Trust

#### *Baseline data collection:*

Modality of data collection: After consent was given, MYCaW® data was collected at baseline by community matrons or link workers presenting the consent sheet and tool to people on paper during the first consultation session. MYCaW® asks every person to identify their concerns that most bother them and then to rate the severity of these concerns and the level of their wellbeing. Where possible patients completed their own forms, however, sometimes the member of

staff scribed the responses for them by writing the responses of the patient down verbatim (this was paramount as the voice of the individual is required for MYCaW® data). There was also opportunity for a proxy informal carers to fill in the questionnaire on behalf of the patient if this was needed, again they were asked to write verbatim what the responses were.

Depending on how the service was accessed by the patient, data was collected either face-to-face using paper forms, or over the phone, or via videocall. Face-to-face the data was collected by paper forms, which patients could write on – or others could scribe for them. Over the phone/video call the data collection was done by the tool being read out via a script (see below for script) which ensured consistency of data collection with MYCaW® 0-6 scale presentation. When the tool was delivered over the phone/ video call then responses were typed into either SystmOne to record responses. When the data was captured face-to-face, then the written responses were photographed on the member of staff's work phone and then emailed to an administrator who input the data into the patient's digital record (SystmOne). The photograph was then deleted, see below for flow chart.

*Follow-up data collection:*

Opportunity for data collection from patient, proxy or member of staff was allowed at the follow-up data collection time. Follow-up data collection was collected either face-to-face, or via video/phone call as in the first data collection time point. No paper version of the tool was shown at follow-up with face-to-face data collection, instead the original concerns written down at the first time point were found on the SystmOne notes system and read out or shown to the patient on the digital display. The patient simply then had to provide their answer to the Likert scale of how the concerns and wellbeing were scored at follow up. Two free-text open questions were then asked, and the practitioner captured the responses from the patient or proxy caregiver verbatim on the digital system.

**Data collection process at South Cots frailty service**

As above but using EMIS as well as SystmOne.

Document 4 - for Consent form for MYCaW® project and MYCaW® tool



**Measure Yourself Concerns and Wellbeing (MYCaW®)**

<b>First MYCaW® Date:</b>	<input style="width: 90%;" type="text"/>	<b>Second MYCaW® Date:</b>	<input style="width: 90%;" type="text"/>
---------------------------	--	----------------------------	--

	Face-to-face	Telephone	Video Consultation
<b>Method of delivery:</b> Please tick relevant box			

	Person	Carer on behalf of person e.g. family	Staff member on behalf of person
<b>Completed by:</b>  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.

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

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

SAMPLE COPY ONLY – LICENCE FROM MEANINGFUL MEASURES REQUIRED

# Measure Yourself Concerns and Wellbeing (MYCaW®)

## First form

Today's Date: \_\_\_\_\_

*Please tick the relevant boxes below so we can understand more about the data collection:*

### I am a: (please tick)

- Patient completing this on my own
- Carer completing this about myself
- A carer supporting someone to complete this (e.g. family member)
- A professional supporting someone to complete this (e.g. nurse or link worker)

### This was completed: (please tick)

- During a face-to-face appointment
- During a phone/ video consultation
- At home, returned by post
- Via an online survey

Please write down one or two concerns or problems which you would most like us to help you with.

1.

2.



# Measure Yourself Concerns and Wellbeing (MYCaW®)

## Follow-up form

Today's Date: \_\_\_\_\_

Please tick the relevant boxes below so we can understand more about the data collection:

**I am a (please tick):**

- Patient completing this on my own
- Carer completing this about myself
- A carer supporting someone to complete this (e.g. family member)
- A professional supporting someone to complete this (e.g. nurse or link worker)

**This was completed: (please tick):**

- During a face-to-face appointment
- During a phone/ video consultation
- At home, returned by post
- Via an online survey

Look at the concerns that you wrote down last time (please do not change these).

Now circle a number below to show how severe each of those concerns or problems is now:

**Concern or problem 1:**

 0 1 2 3 4 5 6   
 Not bothering me at all Bothers me greatly

**Concern or problem 2:**

 0 1 2 3 4 5 6   
 Not bothering me at all Bothers me greatly

**Wellbeing:**

How would you rate your general feeling of wellbeing now? (How do you feel in yourself?)

 0 1 2 3 4 5 6   
 As good as it could be As bad as it could be

**Other things affecting your health**

The support that you have received here may not be the only thing affecting your concern or problem. If there is anything else which you think is important, such as changes which you have made yourself, or other things happening in your life, please write it here.

**What has been most important for you?**

Reflecting on your time with us what were the most important aspects for you?

**Thank you for completing this form**

## Document 5 - MYCaW<sup>®</sup> implementation guidance developed by Gloucestershire services in collaboration with Meaningful Measures

### **Guidance for staff working with older or vulnerable people**

**MYCaW<sup>®</sup> 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<sup>®</sup> 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<sup>®</sup> on the person's 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<sup>®</sup> 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 respects your professional judgement in these situations.
- It is good practice to record why MYCaW<sup>®</sup> 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](mailto:hello@meaningfulmeasures.co.uk)

## Document 6 - Script to use when explaining MYCaW® 0-6 scale over the phone/ video call

We'd like you to think about your concerns and score how much they are bothering you.

We have a number scale to use to show how much your concern bothers you, and in a moment we will ask you to select a number that reflects how severe your concern is. First let me just tell you the scoring:

- 0 is the lowest number you can choose, this means your concern is not bothering you at all.
- At the opposite end is 6 which is the highest number you can score - this means your concern bothering you greatly, it is the most severe it could be.

So, 0 - lowest or best score, your concern not bothering you at all, and 6, worst/most severe score, your concerns is bothering you greatly.

[Check understanding] - does that make sense?

OK, so thinking about your first concern ...[read it out to the person] - Please choose a whole number on that 0 to 6 scale that reflects how much this is bothering you. 0-not at all, 6 as bad as it can be, or perhaps somewhere in between?

*[they may say it is quite bad, so then you could say , 4/6, 5/6, or 6/6 bad? or they might say about average, and 3 is in the middle, so 3 would be around average.]*

So now we are going to do the same thing for your second concerns ...[read it out to them]. Thinking about that concern, choose a whole number on that 0 to 6 scale that reflects how much this is bothering you.

Prompt if needed: 0-not at all, 6 as bad as it can be, or perhaps somewhere in between?

*[they may say it is quite bad, so then you could say , 4/6, 5/6, or 6/6 bad? or they might say about average, and 3 is in the middle, so 3 would be around average.]*

### **NB**

It is OK to orientate their words towards parts of the scoring scale, you just can't decide what score you think their words translate into, they need to pick that number.

## Document 7 - Flow chart MYCaW® data collection process by clinical teams (CC@H)

### MYCaW® score process

#### During initial assessment / goal setting with person

Community Matron (CM)/ Wellbeing Coordinator (WBC) completes MYCaW® proforma with person, person either completes it themselves or CM / WBC reads out the questions and completes the proforma on behalf of the person



Write person's NHS Number, full name and date of birth on form.

Write date proforma first completed (date of visit)

Write down one or two problems which the person would most like CC@H to help them with (write in boxes on form).

Always write in the first person "I would like help with" I want to"

For Problem 1 circle a number to show how severe each problem is (nos. range from 0 – 6)

For Problem 2 circle a number to show how severe each problem is (nos. range from 0 – 6)

Ask the person how they rate their general feeling of wellbeing now? Circle a number (nos. range from 0 – 6)



CM / WBC enters the number for problem 1 onto SystemOne

CM / WBC enters the number for problem 2 onto SystemOne

CM / WBC enters the number for Wellbeing score onto SystemOne



CM / WBC takes a photograph of the proforma (pages 1 and 2) on their mobile phone and **immediately** emails the photograph to the CC@H administrator



CM / WBC places the completed paper version of the MYCaW® proforma in the patient's orange folder (which is kept in the patient's home) so that this can be viewed by other members of the CC@H team (OT, physio, dietitian, WBC)



**Within 24/48 hours** the CC@H administrator opens the email from CM / WBC matron and the attached photograph of the MYCaW® proforma. The CC@H administrator enters the answers of the MYCaW® proforma onto the MYCaW® Excel spreadsheet.



CC@H Administrator checks numbers for Problem 1 and 2, and wellbeing score have been entered on SystemOne



The CC@H administrator attaches the photograph file (of the MYCaW® form) to the patient's SystemOne record



The CC@H administrator closes the MYCaW® proforma photograph file and closes the email. The CC@H administrator deletes the email.

## MYCaW® score process

### On discharge / when reviewing goals / during last visit

CM / WBC completes MYCaW® proforma with person, person either completes it themselves or CM / WBC reads out the questions and completes the proforma on behalf of the person



Write person's NHS Number, full name and date of birth on form.

Write date proforma first completed (date of visit)

Remind person of their answers from the first form, do not write new problem/s.

For Problem 1 circle a number to show how severe each problem is (nos. range from 0 – 6)

For Problem 2 circle a number to show how severe each problem is (nos. range from 0 – 6)

Ask the person how they rate their general feeling of wellbeing now? Circle a number (nos. range from 0 – 6)

Ask the person about *other things affecting their health*, write response on proforma

Ask the person *what has been most important for them*, write response on proforma



CM / WBC enters the number for problem 1 onto SystemOne

CM / WBC enters the number for problem 2 onto SystemOne

CM / WBC enters the number for Wellbeing score onto SystemOne



CM / WBC takes a photograph of the proforma (page 3) on their mobile phone and **immediately** emails the photograph to the CC@H administrator



CM / WBC places the completed paper version of the MYCaW® proforma in the patient's orange folder (which is kept in the patient's home) so that this can be viewed by other members of the CC@H team (OT, physio, dietitian, WBC)



**Within 24/48 hours** the CC@H administrator opens the email from CM / WBC matron and the attached photograph of the MYCaW® proforma. The CC@H administrator enters the answers of the MYCaW® proforma onto the MYCaW® Excel spreadsheet.



CC@H Administrator checks numbers for Problem 1 and 2, and wellbeing score have been entered on SystemOne



The CC@H administrator attaches the photograph file (of the MYCaW® form) to the patient's SystemOne record



The CC@H administrator closes the MYCaW® proforma photograph file and closes the email. The CC@H administrator deletes the email.

## Document 8 - for summary of DPIA and link to document

### Data flows

- The questionnaire is used as part of the care planning conversation by staff within the Gloucestershire Health and Care NHS FT Complex Care at Home Service, South Cotswolds Frailty service within primary care and frailty nurses employed by North and South East Gloucester PCN.
- Patients are informed by staff of the purpose of collecting the data to enable development of the frailty framework and given the option to opt out. They are also informed that they can withdraw consent by speaking to the clinician or wellbeing coordinator working with them, who will ensure their data is not included in the report.
- Data is entered by the designated clinician or wellbeing coordinator into the clinical system via a MYCaW<sup>®</sup> template (EMIS) or MYCaW<sup>®</sup> questionnaire (TPP).
- A report containing the MYCaW<sup>®</sup> data and associated demographics as outlined, is generated within the service/practice from the clinical system and exported as an excel spreadsheet.
- The qualitative and quantitative data is reviewed to ensure no PID other than that agreed is included.
- The password protected spreadsheet is emailed via secure email (nhs.net) from the service/practice to the Meaningful Measure nhs.net email address.
- The data is analysed by Meaningful Measure under the terms of the MOU between Meaningful Measures, NHSEI, GHC, GCCG, South Cots PCN and North and South Gloucester PCN.
- A framework of concerns and associated report developed using aggregated anonymised data. The email with the spreadsheet is deleted once the report has been completed and sender is informed.
- The report and framework of concerns are shared with Gloucestershire CCG and the NHSE/I South West Integrated Personalised Care team. A summary report is developed for public distribution.

See document 9 for the SOP outlining data transfers between GHC and Primary Care, and Meaningful Measures.

### Data retention

The data is password protected and stored securely on Google Drive by Meaningful Measures LTD, who are DSPT compliant (Standards Met 2019/20, registered as 8KM96 on DSPT website). Access is only via a secure unique link available only to Meaningful Measures staff. After completion of the project, anonymised questionnaire responses (with all personal data removed) will be kept for up to seven years to contribute to development of a larger data set in the future. The data sender (GHC, S Cots PCN and North and South Gloucester PCN) will be emailed once the deletion is complete to confirm the personal data has been removed from the data set.

The full NHSE/I DPIA is available here:



Data Protection  
Impact Assessment (0

## Document 9 - Standard Operating Procedure for MYCaW® project for processing data and sending to Meaningful Measure for data transfer

	<b>Activity</b>	<b>GHC CC@H</b>	<b>Primary Care SCFS</b>
1.	Questionnaire including front sheet is completed using electronic template	CC@H staff	Frailty matron or wellbeing coordinator
2.	PRIMARY CARE: Report is run within EMIS/ S1 and exported as excel spreadsheet	CC@H BI staff	SCFS staff
3.	GHC: Report is run with S1 and exported as an excel spreadsheet	CC@H BI staff	SCFS staff
4.	The ages of people are converted to 5-year age bands	CC@H BI staff	SCFS staff
5.	The qualitative data is reviewed to ensure no patient identifiable information is included e.g. Names of patients or others Geographical location Occupation	CC@H BI staff	SCFS staff
6.	The finalised spreadsheet is password protected using agreed password	CC@H BI staff	SCFS staff
7.	The finalised spreadsheet is sent via nhs.net email to SEERS, Helen (NHS ENGLAND & NHS IMPROVEMENT - X24) <a href="mailto:helen.seers@nhs.net">helen.seers@nhs.net</a> at meaningful measures for analysis.	CC@H BI staff send to SEERS, Helen (NHS ENGLAND & NHS IMPROVEMENT - X24) <a href="mailto:helen.seers@nhs.net">helen.seers@nhs.net</a>	SCFS staff send to SEERS, Helen (NHS ENGLAND & NHS IMPROVEMENT - X24) <a href="mailto:helen.seers@nhs.net">helen.seers@nhs.net</a>
8.	Meaningful measures acknowledge receipt of the email and spreadsheet	HS to acknowledge (add read receipt from the sender)	HS to acknowledge (add read receipt from the sender)
9.	Helen Seers from Meaningful Measure to download password protected excel data file from NHS email to Meaningful Measures secure google drive.	HS to move data file to Meaningful Measures google drive	HS to move data file to Meaningful Measures google drive
10.	On acknowledgement of receipt, the report is deleted from the server where it is stored in GHC or primary care. The email to Meaningful Measures with the spreadsheet attached is also deleted from the email account	HS to delete email, and tell sender	HS to delete email, and tell sender