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# Measuring patient outcomes and experiences in Dudley

Findings from a feasibility pilot evaluation

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The  
Strategy  
Unit.



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# Background to the project



# Summary

- This slidepack reports the findings of a feasibility pilot and evaluation with two GP practices in Dudley, conducted between October 2017 and January 2018. The pilot tested the use of three Patient Reported Outcome/ Experience Measures (PROMs/PREMs), before their wider roll-out from April 2018, across the whole of the MCP. The measures tested were: IntegRATE, CollaboRATE, and WEMWBS (short and long version).
- Practice staff were supported by ICF and NHS Dudley CCG to administer the measures to two different patient cohorts: 1) patients taking part in a Long Term Condition (LTC) review, and 2) patients being supported by a multi-disciplinary team (MDT).
- We present here key implementation learning points, stakeholder views and a descriptive analysis of the findings of the measures from a limited sample of 17.
- Conclusions and recommendations for future use of these measures are presented for consideration, before wider roll-out across the MCP.

# Introduction

## Why are PROMs and PREMs important?

- Person-centred care requires an understanding of the experience and impact of care, from the patient's own perspective. Systematic use of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) is the first step to achieving this.
- At an individual level, these measures can be used to support (and improve) the delivery of care, e.g. for the routine assessment and management of patients with long term conditions (LTCs). They can also be used to improve communication between healthcare professionals (HCPs) and patients, to enhance patient involvement and to ensure the personalisation of care.
- At a whole-system level, they can be used to provide evidence on the performance and quality of services, support the measurement and benchmarking of services and inform service redesign.

## PROMs and PREMs in the MCP

- The new Multispecialty Community Provider (MCP) in Dudley (which will be in contract from April 2018) will be expected to measure patient outcomes and experiences – this is part of its objectives to **improve access to care, continuity of care and care co-ordination.**
- In September 2016 ICF conducted a rapid review of generic\* PROMs and PREMs for NHS Dudley CCG. This work informed the selection of a number of measures which will be embedded into the MCP contract.
- The rapid review assessed 8 PROMs, 5 PREMs, and 3 carer specific measures against 9 criteria including: usefulness; meaningfulness; user-friendliness, feasibility; responsiveness; cost; validity; reliability; and widespread usage.

\*Generic measures look at broader outcomes (such as quality of care or quality of life) rather than specific disease-related outcomes and experiences.

# Introduction

## PROMs and PREMs in the MCP

- Following the review by ICF, NHS Dudley CCG selected several PROMs and PREMs deemed suitable to use with different local health populations.
- These include:
  - [Warwick and Edinburgh Mental Wellbeing Scale](#) (WEMWBS). Available in 14 scale and shorter 7 scale item version (SWEMWBS). This can be used to monitor mental wellbeing, covering both feeling and functional aspects of mental wellbeing.
  - [CollaboRATE](#). A short three item scale that can be used to measure experiences of shared decision making after a consultation.
  - [GP Patient Survey](#). A survey run by Ipsos MORI that can measure people's access to quality care.
  - [ASCOT SCT4](#). A four-level tool for measuring social care related quality of life (SCRQoL), with domains which can be used to understand general wellbeing.
  - [ASCOT Carer](#). A version of ASCOT asking about aspects of quality of life relating to caring.
- These tools and measures were considered as options to pilot with practices. As part of this project the CCG were also keen to potentially understand patient-reported outcomes related to the primary-care MDT model.
- ICF therefore recommended they also consider a PREM related to integrated care, [integRATE](#). Developed by the team behind CollaboRATE, it is a four question scale which provides a brief tool for measuring levels of coordination, working relationships information provision and sharing. This was added to the 'menu' of options for this project.
- ASCOT was not included on the menu for this project because its questions are already included in a national survey (Personal Social Services Adult Social Care Survey) which may be a more cost-effective way of implementing this measure.

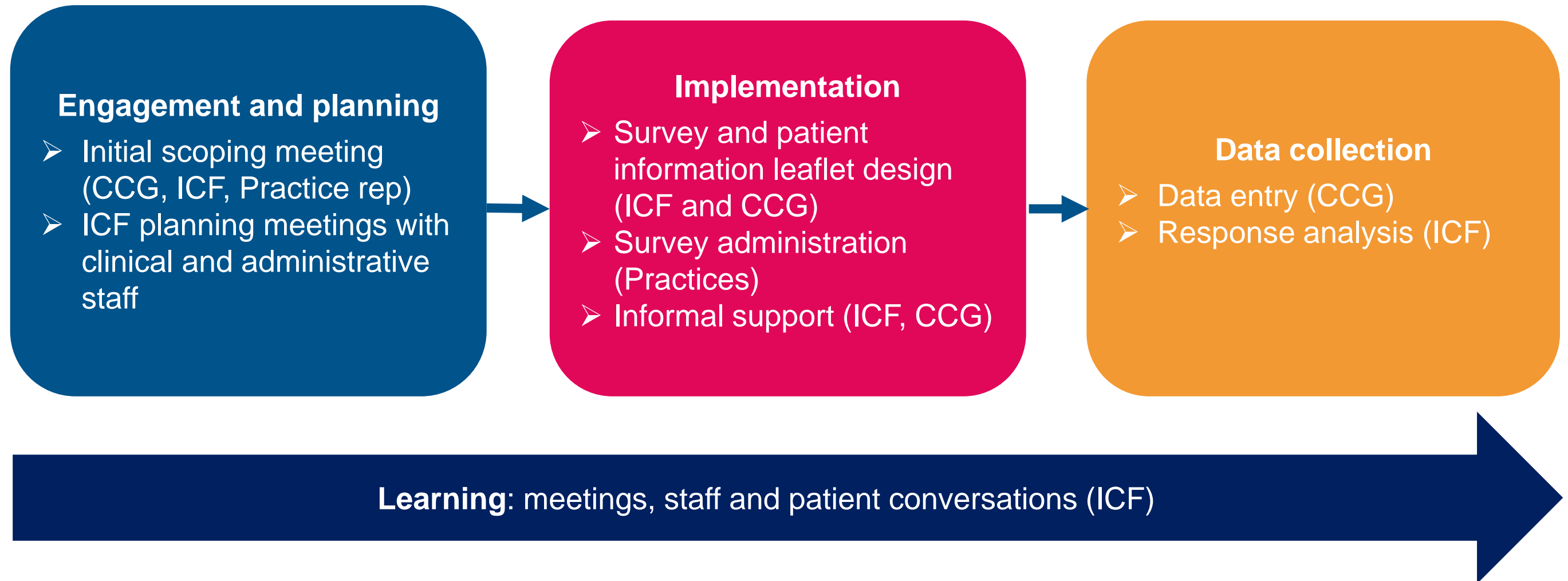
# Methodology

- This feasibility pilot was a collaboration between the CCG, ICF, and two Dudley general practices which agreed to participate after a CCG-wide invitation was issued.
- The pilot and evaluation took place between October 2017 and January 2018. An engagement and planning phase took place to discuss and select the measures to be tested, and suitable cohorts for them to be tested with.
- The implementation process was developed with the practices. Chosen measures were combined to create bespoke patient surveys, approved and administered by the practices (see next slide for more details), with support from the CCG.
- We consulted with clinical and administrative staff (n=5) to gather their views on the language and suitability of measures; barriers and enablers for implementation and learning for the future. We also interviewed 5 patients who had completed the measures.
- Patient survey responses were collected by the CCG via freepost postal returns. Due to the limited number of returns (n= 17\*) we have only been able to provide a descriptive analysis.
- ICF also provided informal support during implementation while the CCG provided resources (data entry support, materials, and postage).

\*Number received up to 12 Jan 2018.

# Methodology

The diagram below summarises the method employed.







# Implementation learning



# Developing the survey design

- Our previous review of PROMs and PREMs for Dudley CCG recommended that the local population should be segmented and appropriate measures used accordingly.
- Planning meetings with practices were used to workshop ideas for appropriate patient groups, measures, admin and response methods to use – these are summarised on the next slide, see [Table 1](#).
- Both practices agreed to test IntegRATE and CollaboRATE with MDT patients but felt that postal methods were the only way to reach them. It was agreed to send surveys to those patients being discussed in December at the MDT meeting. In one practice this was changed to patients discussed by the MDT over a year who were considered able to comment on team coordination.
- Practices agreed that patients with LTCs should be asked about their mental wellbeing (WEMWBS) and shared decision making (CollaboRATE). One of the practices was happy to trial the longer version of WEMWBS, whilst the other felt the short version would be most appropriate. LTC reviews were considered an appropriate opportunity to distribute surveys. Nurses in both practices agreed to do this.
- The initial intention was to use the WEMWBS measure twice to measure change over time. Procedures were put in place to enable this to take place; however delays in the ‘going live’ date meant that using this measure to also offer a snapshot view was more feasible.

# Developing the survey design

**Table 1 Cohort and measure combinations**

Cohort	Measure	Outcome	Experience	Distribution and completion method	Number printed*
MDT 1	IntegRATE CollaboRATE		Co-ordinated/ integrated care; shared decision making	Postal or online	70
MDT 2	IntegRATE CollaboRATE		Co-ordinated/ integrated care; shared decision making	Postal or online	40
LTC 1	WEMWBS CollaboRATE	Mental Wellbeing (14 questions)	Shared decision making	In-person + postal or online	200
LTC 2	SWEMWBS CollaboRATE	Mental wellbeing (7 questions)	Shared decision making	In-person + postal or online	200

\*Practices did not confirm number of surveys distributed

# Planning for implementation

## Engagement with practices took time

- Engagement and gaining buy-in from the practices required more time than originally planned.
- We developed an offer to emphasise the benefits for the whole practice and their patients in taking part. Persistent direct communication with key practice contacts was necessary to establish participation.
- At one practice, management staff were enthusiastic but required clinician sign-off before proceeding. The planning with a wider practice group at the other practice led to more efficient decision making.

## Registration was necessary to use the tools

- The tools selected are all free of charge when used for non-commercial reasons. Nevertheless the developers of WEMWBS and CollaboRATE request that people register to use them. IntegRATE is still currently under further development but may also require registration in the future.
- The CCG registered for using the measures on behalf of the practices.

# Planning for implementation

## We made adjustments to suit the cohorts

- While the practices agreed to trial questions from IntegRATE and CollaboRATE with MDT patients, there were some queries about whether they were the correct population with whom to discuss these aspects of care.
- This was because patients may not be aware they are being discussed by an integrated team, or interact with so many professionals that comments on shared-decision making may be taken out of context.
- CollaboRATE is usually intended to be administered directly after an appointment with a particular health professional. As patients under the MDT can come into contact with many different health and social care professionals, a question needed to be added to the patient survey to establish who that was.
- This was also why it was felt that MDT surveys could only be distributed by post— as it was not practical during the pilot to brief or provide surveys to every service MDT patients might interact with.
- Both practices made the suggestion that the surveys also be provided in an online format for housebound patients to complete, who are not able to reach a post office to return the freepost paper format. Therefore a web link was provided in patient information literature that accompanied the survey.
- There was some discussion about technological literacy (and we received no online survey returns) but it was still felt it was important to provide different accessible options to enable people to participate.

# Planning for implementation

## We tried to avoid in-consultation survey burden for patients

- For one practice they were keen that the pilot did not impose too much on LTC patients, who already have to respond to the other questionnaires as part of their LTC appointments with the nurse.
- As LTC consultations have recently changed to encompass discussions about more than one condition there is also limited time to support patients to complete a PROM or PREM. Nurses therefore briefed LTC patients about the patient survey before distributing them but asked them to take it away to complete.

## We planned ahead for repeat measurement

- As it was initially intended to measure whether patient mental wellbeing had changed as a result of care, two measurements needed to be taken; a baseline benchmark and at an agreed repeat point (e.g. after 6 months).
- During the pilot it was more practical to measure only once but contingency plans were made to enable future repeat measurement. Practices were asked to keep a register of LTC patients (by EMIS number, and survey code) who had received a survey in order to support future repeat measurement with the same patients. While it would be possible to also do this for MDT patients it was not attempted for this pilot.

# Practical considerations in delivery

A number of practical considerations arose out of the pilot

## Timing

There were fewer LTC appointments during December so not all printed surveys were able to be distributed across the two practices. January to March was suggested as a better period for yielding more responses.

## Resources available (1)

Resource was cited as a barrier by stakeholders during the planning phase. Additional resource was therefore put in by the CCG – e.g. printing, postage, survey production and data entry. ICF also supported delivery through project management, and developing the patient information leaflet and survey.

## Resources available (2)

As patient contact details cannot be shared, postal surveys (e.g. for MDT patients) needed to be sent out by practices. In addition, admin support was needed to produce a report of eligible MDT participants.

## Survey coding and data entry

In order to support repeat measurement, survey identifiers were added to surveys. Practices kept a record of surveys distributed by survey identifier cross-referencing EMIS numbers (for internal use only). This was to enable the same participants to be asked to participate again.

## Maximising returns

The limited patient survey responses may indicate that more intense personal support is required to encourage people to respond to the survey. Patients we spoke to were not engaged and did not provide meaningful insights.

# Stakeholder views





# Stakeholder views

The following reflections by staff were gathered during planning workshops and individual interviews.

## Acceptability of measures

CollaboRATE, integRATE and WEMWBS (both versions) were generally felt to be acceptable measures to use with patients. The following specific observations were made:

- The brief number of questions for CollaboRATE and integRATE were welcomed by staff concerned about patient concentration spans and motivation to complete a survey.
- A practice manager felt that CollaboRATE asks similar questions to those included in the GP Patient Survey.
- One healthcare professional (HCP) felt that the negative phrasing of integRATE was rather “leading” and they were concerned about reading age compatibility. They were reassured that the wording has been tested with patients.
- Another HCP expressed uncertainty about both the measures considered for MDT patients but felt that it was important to test them. *“We weren’t sure if either of them worked but we came to a mutual agreement to try...”*
- One practice chose the SWEMWBS because they were concerned about a particular question on the longer version – they thought that asking people to reflect on whether they feel loved (one of the questions on WEMWBS) may cause some patients distress. The other practice did not feel the same concern.
- There was a discussion about the ethics and disclosure requirements relating to using WEMWBS as its findings might indicate significant patient worries about their mental wellbeing. It was also discussed that as patient responses were anonymous, that it would not be possible to follow up a participant.

# Stakeholder views

## Using the measures

- The decision to distribute surveys by post and at the end of LTC consultations was a practical one, relating to availability of resources and time. However participants expressed concerns during planning stages that these methods would not encourage patients to return them. Given the limited number of returns, some of this concern appears warranted. A GP reflected: *“If you’re asking me if it was the best way to do it – no , but in the current climate...was it the only option we had, yes I think it was.”*

## Suitability of patient cohorts

Both practices raised concerns about the suitability of asking patients under the care of the MDT to complete this kind of survey:

- Concerns raised during the planning stage were related to their ability to return the survey by post and whether shared decision making was relevant to them.
- During the planning meetings the newly introduced Care Coordinators were suggested as professionals that might be suitable to take a role in physically distributing surveys to MDT patients or supporting them to complete it.

- One practice manager described how they found it difficult to identify patients to send the survey to as the nature of this cohort means that many are gravely ill *“too ill...[The GP] was concerned about their ability to undertake the survey and the likelihood that they would.”*
- In a change from the agreed method, one practice decided to contact MDT patients discussed in meetings throughout the year who they felt were aware they were working with a team of health professionals (in order to make the integRATE questions relevant). They felt constrained (and this was echoed by the other practice) by the fact that some MDT patients will not know they are being discussed by the MDT.
- Staff from both practices felt that it was very important to talk to patients from the LTC cohort: *“ For me, it’s more about [people with] chronic diseases . I think it catches a lot of people with the biggest number of visits to services.” (GP).*

# Stakeholder views

## Meaningfulness of questions

- Both practices felt that it was important to ask people with LTCs about their general mental wellbeing *“as we know that when people are not feeling “well” they use the most resources.” (GP)*
- One HCP suggested that these are also outcomes that MDT patients should be asked about rather than about other aspects of care *“We hope that by them getting better at more joined up care that it... will have an effect on their mental wellbeing but I don’t think shared decision making is quite such a big thing in that group.”*

## Ideas for the future

Other suggestions put forward for better ways to use PROMs and PREMs included:

- One HCP reported that in an ideal world they would follow the “gold standard” of *“having someone in there with the patient filling it in...they can answer any questions...if the patient isn’t sure what something means.”* However this option was viewed as completely *“impractical”* in terms of time and cost and *“taking people away from what they should*

*be doing.”*

- At one practice diabetes patients were previously supported to complete a survey over the phone by a practice secretary. However a practice manager worried that patients are suspicious of being contacted by phone and may need a two-step process to establish rapport first.
- Another practice manager suggested that the processes set up to support the Friends and Family Test, which they praised for being *“streamlined,”* were effective because they were *“relatively hassle-free”* for her practice staff. Text messages are sent to patients after appointment reminders and their replies are captured by an online programme that automatically generates reports. However, the nature of the questions of the PROMs and PREMs piloted in this project may not make them suitable for this method of contact.
- A last suggestion from a practice manager, was to use the EMIS-integrated template used in LTC reviews to prompt clinical staff to ask the questions contained in these PROMs and PREMs. She acknowledged that this might meet with some resistance from clinical staff but felt it had advantages as an administrative process in terms of generating reports.

# Stakeholder views

## Challenges in gaining patient feedback

- In order to gain feedback from patients on their views about the PROMs and PREMs we included a contact box on the patient survey.
- 5 patients provided their contact details to indicate they were happy to be contacted.
- When contacted, it was difficult to gain meaningful insight from the patients for the following reasons:
  - Memory challenges – one person could not remember completing the questionnaire
  - Conflicting concerns – patients wished to discuss their conditions rather than the questionnaire.
- Two patients were able to comment that they were happy to be asked about care in this way.



# Patient survey findings

# Patient survey responses

## Outcomes and experiences of patients

During the evaluation period (27 Nov 17 to 12 Jan 2018) we received a limited number of survey responses, 17, all by post. This poses challenges for analysis; e.g. CollaboRATE recommends that an overall CollaboRATE Score only be calculated when all three CollaboRATE items have been completed for at least 25 clinical encounters for the particular provider, clinic, or other group of interest. In addition, among the LTC patients only one completed the longer WEMWBS measure. Nevertheless the following is presented as an illustration of what kind of information can be available from wider use of these PROMs and PREMs.

### Number of responses received to 12 Jan 2018

	Practice 1	Practice 2
LTC	7	3
MDT	1	6
Subtotals	8	9
Total	17	

### Notes on tools and scoring

- CollaboRATE is comprised of 3 items. Scores range from 0-9, with higher scores representing more shared decision making.
- The WEMWBS (14 items) total score ranges from 14-70, with higher scores indicating higher positive mental well-being.
- The SWEMWBS (7 items) total of the raw scores are converted to metric scores using a conversion table. The total metric scores range from 7 to 35, with higher scores indicating higher positive mental well-being.
- IntegRATE is comprised of 4 items, is still in development and no scores are currently used – a descriptive narrative is provided.

# Patient survey returns

## Long-term condition patients

- All ten patients with LTCs who responded to the survey indicated that they had experienced a very high level of shared decision making in regards to their care. Nine of these respondents gave the highest possible score of nine, whilst one respondent felt that almost every effort was made to help them understand their health issues (rated eight out of nine on that item). See [Table 2](#) for a summary of the results.
- Nine calculated SWEMWBS scores indicated higher positive mental wellbeing. Looking at specific statements making up the scores, all respondents felt that they have been able to make up their own minds about things relating to their health care either 'often' or 'all of the time', whilst two thirds of the respondents stated that they had only been feeling relaxed 'some of the time'.
- The patient that completed the WEMWBS measure had an overall score of 48, and on individual statements reported having energy to spare 'none of the time' and 'rarely' felt relaxed. However, they reported that they had been thinking clearly, making up their own mind about things and feeling loved 'all of the time'.

# Patient survey returns

Table 2 LTC survey responses

Patient number	Individual CollaboRATE Score	SWEMWBS or WEMWBS score
1	8.33	20.73
2	9	20.73
3	9	21.54
4	9	23.21
5	9	26.02
6	9	28.13
7	9	48
8	9	Total score not possible*
9	9	Total score not possible*
10	9	Total score not possible*

\*Participant did not complete all items



# Patient survey returns

## MDT patients

- Perceived levels of shared decision-making varied between seven respondents who received care from a MDT. Whilst three patients self-reported a maximum score of nine, others felt that they were less involved in decision making regarding their health issues—three scored six while one participant scored four. See [Table 3](#) for a summary.
- For questions relating to healthcare integration, no particularly strong pattern emerged. Overall, respondents did not often feel uncomfortable because healthcare professionals were not getting along with each other. However, respondents were more likely to find that they had to explain something because people did not share information with each other, or were more often confused because people did not share information.
- One felt that there had been a very high degree of healthcare integration across the professionals involved.

# Patient survey returns

Table 3 MDT survey responses

Patient number	Individual CollaboRATE Score	Health/social care professional seen most recently
1	4	Dermatology
2	6	GP
3	6	GP
4	6	GP and district nurse
5	9	District nurse
6	9	Oncologist
7	9	GP



# Conclusions and recommendations

# Conclusions

- **Engagement posed a challenge throughout.** There was a consistent message during the planning and implementation phases that time and resources are a barrier to being more involved in assisting patients to complete these measures. This presents a challenge as the low number of patient returns indicates (allowing for administrative challenges) that patients also need to be engaged to respond in larger numbers.
- **Some populations were seen as easier to engage than others.** People with LTCs were perceived as an important population to ask to complete these measures and easier to engage with than the MDT patients. Asking patients under the care of the MDT about integration of care was perceived to only be relevant to those patients aware of the teamwork in the first place.
- **Different combinations of measures might have been more meaningful for all.** Mental wellbeing was seen as an important outcome to measure among both population groups, while shared decision making was perceived to be more relevant to discuss with patients with LTCs.
- **There were very few concerns about quality of care.** The small number who responded to the surveys appear generally very happy with the level of care they are receiving from the two practices. Patients with LTCs in particular appeared satisfied with levels of shared decision making. With such a small sample however, we cannot rule out response bias or draw firm conclusions.

# Recommendations

- **Work and effort is needed to get practice buy-in.** Creative strategies are needed to engage primary care in measuring these outcomes and experiences. A longer period of engagement – including for example events and group discussions re. the rationale for using PROMs/PREMs – might benefit the future roll-out.
- **Match the measure and measurement method to the cohort.** Consider the relevant health status, outcomes and experiences of different segmented populations. A whole-system approach may be needed to engage MDT patients, and their caregivers.
- **Forward plan for repeat measurement.** If changes over time are of interest, careful coding, monitoring and recording is needed to engage the same cohort of patients. The timeframe allowed also needs to fit the service – for example embedding the ‘post’ measure in subsequent LTC reviews.
- **Provide different accessible options to enable people to participate.** This would need to be resourced in time and money. As well as online options, practices might consider providing a collection box for surveys to enable people to complete surveys immediately. The feasibility of a ‘response by app’ option could also be tested.
- **Breaking down barriers.** Enabling services within the MCP to support patients to complete PROMs and PREMs appears to be the most promising strategy to improve patient completion rates. Primary care will need to be supported to see this as a valid option.
- **Support culture change across the MCP.** The success of routine use of PROMs and PREMs will ultimately depend on a shift in culture being made across the system. Person-centred ‘mindsets’ are an important first step to achieving changed practice.