

## Research Protocol

# Developing and Enhancing the Usefulness of Patient Experience and Narrative Data (DEPEND)

Full title: Enhancing the credibility, usefulness and relevance of patient experience data in services for people with long-term physical and mental health conditions using digital data capture and improved analysis of narratives

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**HS&DR Project: 14/156/16****Summary of Research**

**Background and relevance to NHS:** Collecting NHS patient experience data is mandatory, with the aim of ensuring high quality, effective and safe services sensitive to population needs. However, there are problems with patient experience data, and the way in which data are processed and summarised. Data often come from structured surveys with low response rates. Frontline professionals are sceptical about the relevance of data based on generic questions to their specific services and are concerned that vulnerable patients and carers may be excluded. Many organisations collect supplementary free text feedback (e.g. comments, complaints, tweets), and there is increasing interest in the potential of patient narratives to provide data that more accurately reflects patient experience, as a lever for service improvement. However, there is limited research on the best ways to: 1. Collect timely and relevant data for specific areas of service provision that meets requirements of staff to inform service improvement; 2. Analyse narrative data that is already collected but not analysed routinely and systematically; 3 Support staff with resources for improving the usefulness of multiple forms of data (narrative and quantitative sources of outcome and experience data); 4 Use data to stimulate service improvement.

**Research question:** Can the credibility, usefulness and relevance of patient experience data in services for people with long-term conditions be enhanced by using digital data capture (quantitative and qualitative), and improved analysis of narrative data?

**Aims & methods:**

**1 Collection & Usefulness- Improve data collection and usefulness by helping people to provide timely, personalised feedback on their experience of services that reflects their priorities, and by understanding needs of staff for effective presentation and use of data.**

We will use qualitative methods to explore perspectives of patients and carers on providing patient experience data. We will use the same methods to investigate perspectives and current practices in use of patient experience data by clinical teams and managers.

**2. Analysis and presentation - Improve the processing and analysis of narrative data alongside multiple sources of qualitative data.** We will use computer science text analytics methods (Spasic et al, 2014) to develop methods for routine, automated and systematic analysis of narrative data. This will provide a necessary resource for analysing data that is currently collected but not analysed systematically. We will also explore ways of presenting analysed patient experience data alongside other indicators of quality, safety and outcomes.

**3 Co-design of toolkit – Improve resources for enhancing collection, analysis and presentation of patient experience data for staff teams in order to maximise the potential for stimulating service improvement.** We will adopt an Experience-Based Design approach (EBD; Bate & Robert, 2007), drawing on the initial qualitative research, the computer science work above, and insights from our PPI group, to co-design ways to enable and support digital data capture, analysis and use of both quantitative and narrative data. These methods will be used to formulate a toolkit comprising: 1. Guidance about collecting patient feedback; 2. New methods for analysing patient feedback data; 3. New methods and guidance for presenting patient feedback data

**4. Implement and evaluate - We will implement a toolkit and investigate its impact for improving collection, analysis and presentation of patient experience data.** We will implement the toolkit and train staff to use the resources in multiple service teams who participated in the initial qualitative research. We will then conduct a process evaluation (Moore, 2015) using qualitative methods to assess the impact of the toolkit on enhancing their credibility,

usefulness and relevance, exploring use of the toolkit and influences on service changes. We will draw on normalisation process theory (NPT; May & Finch, 2009) and a theory of 'absorptive capacity' (Cohen and Levinthal, 1990) to investigate the ability of organisations to acquire and use knowledge. We will analyse time spent collecting and analysing data to estimate costs, and model longer term impacts and costs.

**Care pathways:** The project will focus on services for two exemplar long-term conditions: serious mental illness (SMI); and musculoskeletal conditions (MSK). Recent NHS guidance indicates the need for considering condition-specific tools for collecting and using patient experience data from a patient journey perspective. These groups have high levels of service use in multiple clinical settings, allowing us to consider use of data in different contexts. Both groups commonly have comorbidity, with concerns regarding continuity of care and patient safety, and include people considered to be under-represented in experience data (vulnerable adults, older people, carers).

**Setting:** We will conduct the research in 3 sites: 1 Rheumatology outpatient department in Salford Royal Foundation Trust (SRFT); 2 A community mental health team in Manchester Mental Health and Social Care Trust (MMHSCT); 3 Two general practices within Salford CCG and South Manchester CCG..

Digital data capture is currently being piloted in partner Trusts: SRFT & MMHSCT to capture Patient Reported Outcome Measures (PROM) for these care pathways using a mobile platform developed by team members within Manchester (Palmier-Klaus et al 2012; Ainsworth et al, 2013). SRFT is also in a unique position in having a fully integrated electronic medical record linking primary and secondary care. Consequently, these settings provide a unique opportunity to capture and analyse real-time outcome and experience data together.

## Background and Rationale

### *Collecting and using patient experience data*

Collecting patient experience data is considered essential for enabling delivery of high quality patient-centred care (Ziebland, 2012). In the UK, the collection of patient experience data has routinely been collected via the NHS patient survey programme (by the Picker Institute for the Care Quality Commission - <http://www.nhssurveys.org>). Annual surveys of patient experience such as the national GP survey (1.3 million patients), and the national inpatient survey (64,000) have been conducted retrospectively by mail, with response rates commonly between 30 and 40 percent. Recently, the Francis Report and Berwick review (National Advisory Group on the Safety of Patients in England, 2013) highlighted the need for collecting data that is 'real-time', or as near as possible to real-time, as a means of enabling safe care. The friends and family test (FFT), which asks whether patients would recommend the service to friends and family has been used since 2012 as a means of gathering simple and timely patient experience feedback. A new indicator based on this test has also been included within the NHS Outcomes Framework (DoH, 2012) to 'enable more 'real-time' feedback to be reflected in the framework' (p.11), and this is currently being rolled out nationally. A recent survey (Institute for Innovation and Improvement 2012) found most Trusts report self-completed paper surveys to be the most frequent method of data collection method, but a large proportion are also collecting digital data (55% with the help of an administrator or volunteer; 42% by patients themselves during in-patient stay). Also, 27% of Trusts were planning greater use of digital data capture, and 23% of Trusts stated that the DoH could best help with data collection by providing better technology to help capture and analysis of 'real-time' data (NHS Institute for Innovation and Improvement, 2012).

Recent guidance states qualitative sources of patient experience data to be equally valuable to quantitative surveys and local organisations are currently advised to supplement mandatory survey data with a range of sources including: patient stories, complaints, PALs data, incident reports, and general feedback (NHS Institute for II, 2013). Our NHS partners have varied ways of capturing patient experience such as free text comments via the Trust websites, via Twitter and Facebook, letters to PALs, community forum meetings, and audio-visual stories such as the 'patient voices' programme in Manchester Mental Health and Social Care Trust (MMHSCT).

These sites therefore have a large volume of qualitative data including free text comments. For example, in October 2014 45% (n=463) of respondents to the inpatient Picker survey in Salford Royal Foundation Trust (SRFT) entered free text comments in addition to the structured responses, and 36% (n=71) of patients responding to the Friends and Family Test (FFT) in outpatients also left free text comments.

A priority for research identified in the commissioning brief is: *What research is needed to make data more credible and useful?* The brief acknowledges the different challenges in collecting patient experience data appropriately for different groups (such as carers, and people with mental health problems) and our proposal addresses a key gap in researching ways of capturing timely and relevant data in services for physical and mental health. The work will enable understanding about what data needs to be collected and how best to do this.

Recent research has shown professionals are often sceptical of the relevance of patient experience data to local services because they are based on generic questions rather than being tailored for specific service contexts, and because vulnerable patients/carers are viewed to be excluded (Asprey et al, 2013; Robert & Cornwell, 2011). The brief highlights the need for identifying the most effective ways of presenting patient experience data in a meaningful way for staff. It is crucial to understand the perceived needs of staff regarding the feedback of patient experience data if it is to be used to stimulate service improvements.

As previously mentioned, NHS organisations already collect a wide range of both quantitative and qualitative patient experience data, but there is a lack of understanding regarding how best these different types of data can be presented and used by staff teams. Whilst the collection of qualitative data in the form of open text comments is a large and potentially useful resource, questions remain regarding the representativeness and credibility from the point of view of staff. Also, individual patient narratives may well be powerful, but may not be considered representative of the majority of patient experience. In Trusts collaborating with this project (SRFT and MMHSCT), patient stories are used in the context of board meetings; however, such stories are not routinely viewed by teams of frontline staff, and the views of staff regarding the relevance and use of such data are unknown. This project will fill this gap by using qualitative methods to understand staff perspectives on data requirements.

The project will capitalize on innovative work to capture Patient Reported Outcome Measures (PROMs) digitally for these care pathways using a mobile platform developed by team members within Manchester (Palmier-Klaus et al, 2012; Ainsworth et al, 2013). Moreover, SRFT is in a unique position in having a fully integrated electronic medical record linking primary and secondary care, and an electronic patient record research programme. The collection of electronic PROMs for musculoskeletal disease within SRFT is also part of newly funded work within the CLAHRC programme (the REMORA project, funded by AR UK and CLAHRC) and adds additional opportunity for triangulation of experience and outcome data.

### ***Analysing and presenting patient experience data***

Whilst organizations collect multiple forms of textual and narrative data, these tend to remain unanalysed and/or are only used in an ad-hoc rather than systematic manner. There has been a growing focus on the value of patient narratives in audio-visual, and textual forms, and such stories have been drawn upon for staff training, and service improvement (Kings College/ King's Fund, 2011). However, these represent limited numbers of individual patients and are time consuming to produce. The extensive resources of patient stories now available have prompted some recent research to study how these can be synthesised and used for service improvement (Locock et al, 2014). Similarly, research has shown that analysis of social media posts can provide useful evidence on patient experience (Greaves et al, 2014 a & b). Associations have been demonstrated between patient experience, clinical outcomes and safety (Doyle et al, 2013). However, automated systems are not currently available for identifying narratives that might explain quality and safety indicators. Also, the recent NHS commissioned report on measuring patient experience (Kings College/ Kings Fund, 2011) observes that patient experience is generally reported separately from data on patient safety and clinical outcomes. The report also advocates greater triangulation of data from different sources, including: patient stories, surveys,



patient complaints, PALS data, incident reports, and general feedback. The commissioning brief asks *'How should patient experience data be presented and combined with other information on quality, effectiveness and safety to produce reliable quality indicators?'*

In responding to the above research gaps, we will explore how automated text-analytics techniques can be utilised (Spasic et al, 2014) to provide a means for automated and continuous analysis of relevant textual data which is routinely collected. This is important because such data may be more directly relevant than provided solely in response to structured questions, yet organisations lack capacity to utilise this data effectively. Text-analytics techniques will enable automated and systematic analysis of large sets of qualitative data gathered from multiple sources of patient experience feedback. We can then identify and compare positive and negative aspects of experience with other quantifiable data, including PROM data which is already collected digitally in the service settings focused on providing a unique opportunity to analyse real-time outcome and experience data together and for text-mined data to be semi-automatically integrated with the results of structured questions.

### ***Implementing and evaluating the use and impact of patient experience data***

There is a dearth of evidence on the relative costs of using different ways to collect and use data, and how staff use varied data to inform service changes (Coulter et al, 2014). In addition, whilst there has been an increasing emphasis on the usefulness of narrative data on patient experience, there is a lack of evidence on how stories impact service improvement (Dr Foster Intelligence, 2010). The commissioning brief points to the need for detailed ethnographic research to understand processes underpinning the ways in which organisations, teams and individuals respond to patient experience feedback. The brief highlights a key question needing to be addressed is: *'What kind of organisational capacity is needed in different settings to interpret and act on patient experience data?'*

This study will respond to this research gap in conducting a process evaluation (Moore et al, 2015) of a toolkit (co-designed with patients and staff) for enhancing the collection, analysis and presentation of patient experience data. The evaluation will use qualitative methods to enable detailed understanding of the needs of distinct organisational teams, and how capacity (e.g. for new components such as automated text analytics) may vary according to contextual factors, such as the distinct patient groups they serve, size of team, management structure, and the nature and flow of work. We will draw on Normalisation Process Theory (NPT), which has been developed and used to understand the actions and interactions influencing implementation and how new interventions and practices come to be normalised in health care contexts (May, 2009). We will also draw a theory of absorptive capacity which has been underutilised to date in relation to health care (Harvey et al, 2009). This framework enables distinction between an organisation's ability to acquire knowledge (here, patient experience data) and its ability to process and use this knowledge (Marabelli & Newell, 2014).

### **Evidence explaining why this research is needed now**

Evidence on what patients value most has been incorporated in the NHS Patient Experience Framework (DoH, 2012) including aspects such as respect and dignity; co-ordination/ integration of care; information and communication; physical and emotional care; support for care givers; access and continuity. However, there has been increased recognition of the need to reform and enhance collection and use of patient experience data by focusing critically on what data is collected and how (collection); how data is analysed and used (processing); and assessment of the impact of such data (impact) on driving service change (Kings Fund, 2011). Our proposal is designed to provide evidence in these domains (see Fig.1 in aims and objectives section).

This research is important because NHS organisations are already investing substantial resources in collecting large quantities of data on patient experience, but as highlighted above, there are major inefficiencies in current methods of collecting, analysing and using such data. A recent survey of NHS Trusts has found wide variation in the proportion of patients offered the opportunity to provide feedback, and many Trusts do not have accurate records of response rates.



Many Trusts have reported plans for increasing digital data capture and would like greater technology support for digital data capture and analysis of patient experience data. As the commissioning brief highlights, patient experience data was highlighted as a top priority for the HS&DR programme over the past two years by clinicians, patients, service leaders and managers.

The recent project from the Kings Fund (Robert & Cornwell, 2011) focused on five key pathways including stroke, chronic obstructive pulmonary disease, diabetes, depression and elective hip replacement to explore experience from a patient journey perspective. This report suggests that *'ideally patient experience should to be measured in terms of the journey as experienced by the patient in order to capture transitions in care and continuity issues'*. It also suggests that generic surveys may need to be supplemented with condition-specific indicators. This project will provide important evidence on appropriate ways to collect, analyse and use patient experience data in additional pathways for SMI and musculoskeletal conditions. These are an important focus for research on the use of patient experience data because:

- People with both these types of conditions have high levels of service use in primary and secondary care settings, allowing us to consider needs for patient experience data by multiple clinical teams.
- These long-term conditions invoke common concerns regarding continuity of care and patient safety, often reflected in patient experience narratives (Rhodes et al, 2014)
- Research suggests particular safety concerns in relation to SMI, where aspects of provision of mental health services can affect suicide rates (While et al, 2012)
- There is uncertainty of the applicability of Picker survey frameworks to serious mental illness especially because service users may be forced to receive care
- Both these populations commonly have overlapping co-morbidity and include populations under-represented in current methods to capture data on patient experience: older people with prevalent musculoskeletal conditions, vulnerable younger adults with SMI, and carers in both cases

The research will focus on the use of patient experience data by staff teams in three settings:

A community mental health team (MMHSCT)  
Rheumatology outpatients (OPD) within (SRFT)  
Two general practices within Salford and South Manchester.

The above focus aligns with the NHS Outcomes Framework which highlights key improvement areas for ensuring people have positive experiences of care, including: patient experience of community mental health services; patient experience of outpatients; and access to GP services.

Serious mental illnesses (SMI) such as psychosis affects 2% of the UK adult population. Patients with SMI have lower life expectancy (25 years less than general population, mainly due to physical health problems) and are at greater risk of suicide and self-harm (RCPsych, 2010). These are two examples of key issues where feedback on patient experience might be used to ensure services are meeting physical needs as well as maintaining safety.

In the UK, 14.3% of adults report a chronic musculoskeletal condition (GHS, 2007) and have a major impact on healthcare resources, being one of the commonest reasons for primary care consultation: a longstanding musculoskeletal problem is the reason for 1 in 4 adults being on long-term treatment in Europe. Common problems occur in managing the long-term medications across primary and secondary care, and in meeting needs for secondary care that could be reflected in patient experience feedback and used to stimulate service improvement.

## Aims and objectives

Can the credibility, usefulness and relevance of patient experience data in services for people with long-term conditions be enhanced by using digital data capture, and improved analysis of narrative data?

**Aim 1. Collection and usefulness - Improve data collection and use by helping people to provide timely, personalised feedback on their experience of services that reflects their priorities, and by understanding needs of staff for effective presentation and use of data.**

Objectives:

- Qualitative research to explore perspectives of patients, service users and carers on timing, form (quantitative/ qualitative), and method (ipad, smartphone, paper, group discussion) of providing feedback about experience of services
- Qualitative research to investigate perspectives, needs and current practices on collecting and using patient experience data by clinical teams and managers

**Aim 2. Analysis and presentation - Improve the processing and analysis of narrative data alongside multiple sources of quantitative data.**

Objectives:

- Analyse existing and new narrative data on patient experience using computer science methods for text mining
- Compare analysed patient experience data with other indicators of quality, safety and outcomes; and explore different ways of presenting multiple data sources together

**Aim 3. Co-design of toolkit – Improve resources for enhancing collection, analysis and presentation of patient experience data for staff teams in order to maximise the potential for stimulating service improvement.**

Objectives:

- Co-design new ways of collecting quantitative and qualitative patient experience data digitally (possibilities could include fixed ipads in outpatients with guided support for use, mobile phones in community mental health setting, digital recording of group discussions or individual stories)
- Co-design better methods for interpreting and summarising narrative data on patient experience alongside quantitative data (including outcomes and experience data)
- Develop resources and training for staff for implementation of toolkit

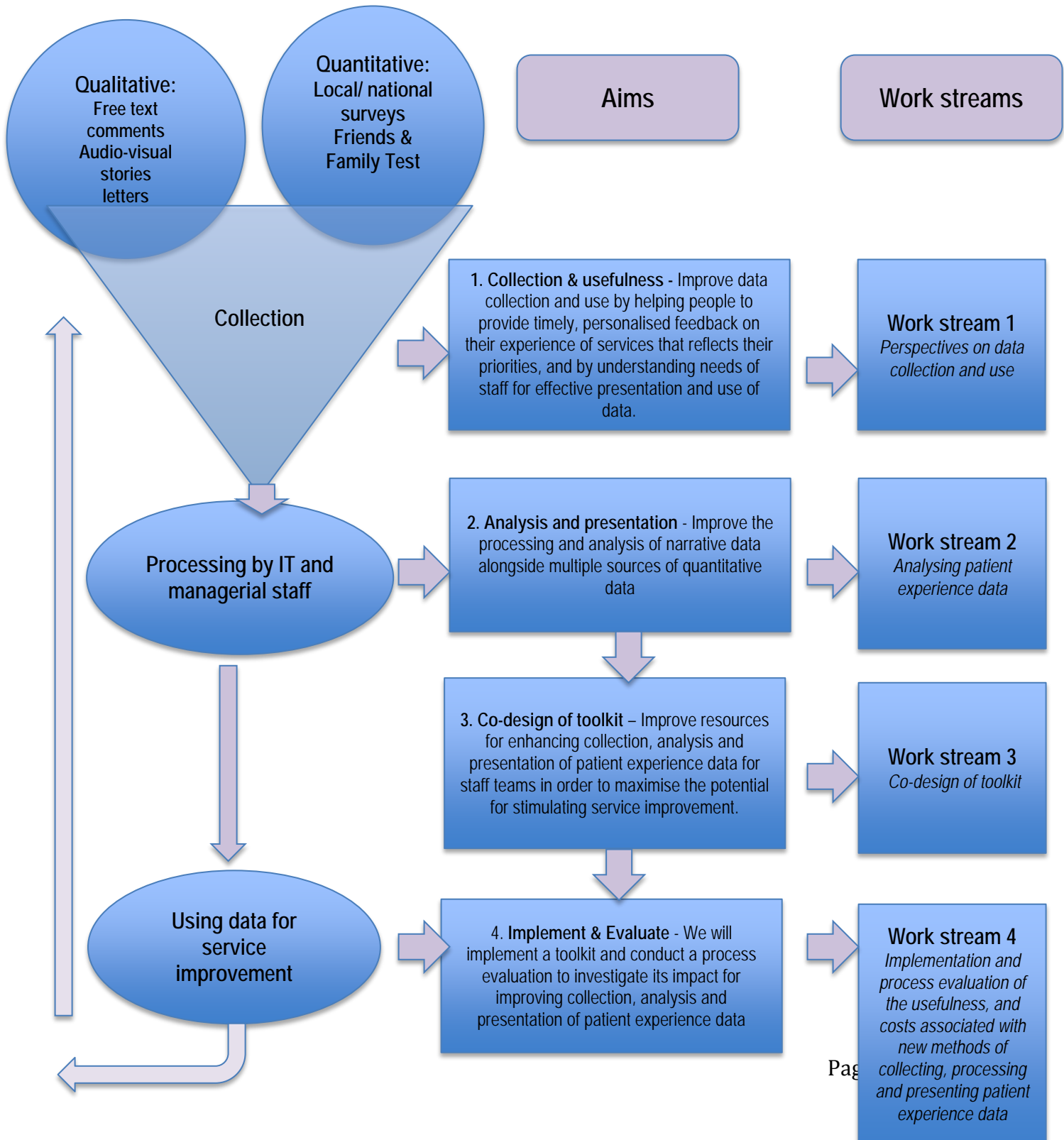
**Aim 4. Implement & Evaluate - We will implement the toolkit and conduct a process evaluation to explore implementation, potential mechanisms of effect, and the impact of context**

Objectives:

- Explore implementation: delivery of training, comparison of text mining with standard analysis, and use of the toolkit components (including time spent and costs)
- Investigate potential mechanisms of effect, including practitioner responses to new ways of collecting, summarising and presenting data, perspectives on the quality and usefulness of data generated
- Explore the impact of context on implementation, including clinical context (serious mental illness and musculoskeletal conditions), setting (community mental health, rheumatology OPD, primary care) and organisational context ('absorptive capacity')

Routine collection and use of  
patient experience data

**Figure 1. Summary of project aims and work streams**



## Research Plan / Methods

The research will be conducted within four work streams (WS):

**WS1 Collection and Usefulness** - *Perspectives of patients and carers on providing patient experience data and perspectives of staff on the use and usefulness of data (Months 1-9)*

*Service providers and key staff:* Qualitative interviews and focus groups will be conducted with key staff to understand perspectives about what data needs to be collected to be useful for staff, and the current practices in each setting. Staff participants will be invited to take part in either a face-to-face interview, or a telephone interview. We will seek views on the credibility and usefulness of different types of data, including narrative and textual sources. Views and experiences of managerial and IT staff will be sought regarding current practices and organisational capacity for using various data sources and current barriers. Recruitment will include clinical staff, managers and IT staff in working within rheumatology outpatients in SRFT (n=20) and a community mental health team within MMHSCT (n=20). We will also recruit primary care staff in two local practices; Salford CCG and South Manchester CCG (n=20) to consider the collection and use of such data in the community setting.

*Service users and carers:* Qualitative interviews and focus groups will be used to understand the perspectives of patients (20 with SMI, 20 MSK) and carers (10 for SMI/10 MSK) on providing patient experience data and to define what forms of data they are willing to provide via different methods. Ethical issues and real or potential barriers to participation will be considered. We will investigate perspectives on providing different data collection formats (e.g. textual, audio, audio-visual, diary) and those structured questions considered most suitable for capturing experiences of the specific service user groups. We will also explore views about *how* to provide feedback to best reflect their concerns and needs. For example, do people want to provide data digitally, and what is the best way to do this – by hand held or fixed devices in service settings, by mobile, or computer? We will consider specific needs within each group. For example, do mental health service users have concerns specific to their care pathway, such as involvement in care planning, and concerns about enforced inpatient care? How can positive and negative experiences of these aspects of care be conveyed? We will also seek views about providing both experience and outcome data simultaneously, and the best ways of capturing these multiple forms of data.

Deliverables: 1. Summary of key perspectives to inform work in WS2 and co-design in WS3; 2. A peer reviewed publication.

### **WS2 Analysis and presentation** – *Analysing patient experience data (months 6-23)*

In WP2, we will develop text mining methods to analyse content of narrative parts of patient experience data, enabling systematic identification and mapping of issues important to patients. Narratives are typically available either as patient/carers stories and interviews or within 'additional comments' boxes in patient surveys, but also in various forms of social media (blogs, tweets, forums, etc.). All these resources should be utilised and integrated to capture and understand patients' comments, which can indicate areas to improve care. However, the volume of these sources is growing – for example, one of the partners (SRFT) collects approximately one thousand comments per month associated with the FTT – which requires automated content analytics for large scale and continuous monitoring of patients feedback.

This work package will use text mining and statistical methods for identification of main topics and themes in such patient narratives, and for mapping them to various experience dimensions (categories), including, for example, treatment effectiveness, side effects and safety concerns, service facilitators and barriers, hospital environment, communication and involvement, coordination of care, family impact and overall impact on quality of life etc. While an initial list of

such dimensions will be established based on existing expertise, clustering methods will be used to identify new topics and concepts that do not map to expected dimensions, indicating new themes of potential interest (e.g. a new type of concern).

Data extracted from individual narratives will be aggregated and presented into a patient experience index.

We will explore ways of presenting analysed patient experience data alongside additional indicators of quality, safety and outcomes.

Deliverables: 1. Text-mining programmes for analysing narrative data to be part of the toolkit developed in WS3, and implemented and evaluated in WS4 2. Interim report to the SSC and HS&DR 3. A peer reviewed publication

***WS3 Co-design of toolkit - Co-designing new tools for improving the collection and usefulness of patient experience data (months 9-12)***

Data collected from patients/carers in WS1 will be summarised and discussed in 4 follow-up focus groups with a proportion of patients/ carers who took part in initial focus groups and interviews in WS1 (approx. 30) and our PPI group to define priorities for capturing patient experience data. We will also conduct 4 follow-up focus groups with staff (1 FG in each site: community MH team, staff in MSK OPD, staff in 2 primary care teams; approx. 30 participants in total) recruited from those who took part in initial focus groups and interviews. These discussions will enable us to define priorities for capturing and using patient experience data.

Data from WS1 and work conducted within WS2 will be used to formulate scenarios of experience and potential solutions using a powerpoint presentation/ film and structured workshop tasks. This approach has been used successfully for our current co-design studies (ClinTouch/ REMORA). These strategies will be used to trigger discussion for designing components of the toolkit.

The development of the toolkit requires some flexibility in keeping with our proposed co-design approach. However, we plan to develop a toolkit with the following main components:

1. Guidance about collecting patient feedback

Guidance will include:

- advice based on findings of the qualitative research about what patients, carers and staff see as important to improve collection. This will include a range of solutions, some which may be technology based. For example, use of fixed ipads in outpatients, or mobile phones in community mental health settings. For example, if patients and staff think that using fixed ipads in outpatients, or mobile phones in community mental health settings would be good solutions, we are able to use ClinTouch as an exemplar mobile platform to test this. One possibility will be to add structured questions and ability to enter free text within ClinTouch, or to use others PDA systems already in use within parts of the organisations. The mode of data capture may vary between the settings because SRFT already uses PDAs for collecting inpatient data, and is planning to pilot use of these in outpatients in the coming months. However, MMHSCT is not currently using such systems for patient experience data and the Trust is currently using the ClinTouch app for collecting PROMs. It will be possible to easily add capacity to the application for capturing patient experience data in order to capture a longitudinal record of patient experience in addition to outcomes. This capability is integrated with the HeRC Data Safe Haven which will provide facilities for secure storage and processing.
- advice on use of open source mobile systems, or design features (if Trusts want to develop their own systems), and advice on how to implement it based on learning from our own implementation

## 2. New methods for analysing patient feedback data

One form of patient feedback collection that is often neglected is narrative and the use of textual comments. This project aims to explore how to incorporate them as part of patient feedback collection and analysis.

A key component of the toolkit will include software tools for analysing narrative feedback, which is currently collected, but not analysed systematically.

This project will produce a free-to-access suite of computer programmes to enable this analysis through:

- (a) Semi-automated identification of key patient experience concepts and themes
- (b) grouping and linking to facilitate systematic exploration of patterns in data

Using the new methods for data visualisation, the extracted data will be presented to the user to facilitate integration and contrasting with other sources. As part of the project we will test out feasibility of adopting this method of analysing data at these sites.

## 3. New methods and guidance for presenting patient feedback data

This section of the toolkit will include guidance on combining the systematic analysis of narrative (element 2 above) with other forms of available data on PROMs, patient experience and quality of care. For example, this might involve embedding appropriate examples of narratives of patient experience alongside quantitative data to illustrate why scores are high or low. It could also include annotations of the text-mining analysis with the feedback from the qualitative interviews. Even if our final version of the method to present data to teams is imperfect, we could provide (eg via Powerpoint/ Word) an annotated walk-through of the trialled version. For example, where we have narratives embedded alongside quantitative data, we might add a margin note that this was viewed as 'really helpful' or 'distracting'. This would allow others to adapt in an informed way.

Guidance will include a range of formats presenting combinations of tables, graphs, word-clouds as well as quantifying themes from the text-mining with examples. Additionally, it may include guidance on using audio-visual presentation of stories, such as those currently presented at Board level, but not routinely within specific local provider teams. The guidance will be contingent upon the views of staff (WS1) on what forms of presentation are most useful and easy to interpret.

In addition to the elements of the toolkit referred to above, patients, carers and staff may want other guidance included to reflect their priorities, and guidance may reflect different priorities for each care pathway. For example, in MMHSCT community forums are currently convened, where service users and carers discuss their experiences of using services. These meetings are not currently audio-recorded, but one possibility is to record and transcribe these meetings and analyse using text mining.

Deliverables: Toolkit for implementation and evaluation in WS4.

***WS4 Implement and evaluate*** – Implementation of toolkit and process evaluation of the usefulness, impact and costs associated with new methods of collecting, processing and presenting patient experience data (months 12-24)

### Training staff to use the toolkit

The qualitative researchers will work with the PI, RF (Daker-White), and PPI co-applicants to run training sessions for the staff in each setting. These will be arranged at convenient times, and last around 2 hours.

These sessions will include:

- a presentation to summarise the findings of the project
- describe key elements of the toolkit



- demonstrate its use to support data collection and use, tailored to each setting

The toolkit will be implemented using small-cycle change (PDSA) approaches. PDSA is already commonly used – training can be provided if necessary through existing programmes - and those involved in implementation will already have had input into the project through co-design of the toolkit being implemented. We will also provide written and online materials and guidance for using the toolkit.

#### Process evaluation

We will conduct a qualitative process evaluation, focusing on underlying processes and mechanisms influencing the adoption and use of the toolkit. This is an accepted method for testing fidelity and quality of implementation for complex interventions, and is also in line with the new MRC guidance on process evaluation (Moore et al, 2015).

In accordance with the guidance, we propose the following components for the evaluation:

#### 1. Description of the intervention and causal assumptions

This description will be informed by the qualitative research in WS1, detailing assumptions about causal pathways in the three distinct contexts (community mental health, outpatients, primary care). Description will also be an output from the co-design work (WS3) which will specify the toolkit and any adaptations for application in the different contexts.

In specifying causal assumptions, we will draw on Normalisation Process Theory (NPT), which has been developed and used to understand the actions and interactions influencing implementation and how new interventions and practices come to be normalised in health care contexts (May, 2009). We will also draw a theory of absorptive capacity which has been underutilised to date in relation to health care (Harvey et al, 2009). See subsequent section on theoretical/ conceptual framework for elaboration of these theoretical frameworks.

#### 2. Implementation

##### *Qualitative evaluation*

We will conduct qualitative interviews/focus groups with patients (n=60) recruited in community mental health teams for SMI (20); secondary care for MSK (20); and primary care for either condition (20). Multiple qualitative methods (interviews, observation and documentary analysis) will be used to examine fidelity, in terms of the degree to which it is implemented and used as intended, and the level of use by staff (n=60; 20 in each setting).

- Interviews and focus groups with patients will focus on their experiences of providing data and any barriers in using new methods.
- Interviews and focus groups with staff will ask about how the toolkit is being used in practice and interpretation and use of patient experience data has changed after using the toolkit. We will include staff with roles in management and patient experience, to consider perspectives on the success of the implementation and organisational capacity for using the toolkit
- We will explore the degree to which workload changes with the new toolkit, especially for key managers (e.g. leads for patient experience), and IT staff; as well as any impact on the work of frontline staff within the study sites

##### *Response rates and participation*

We will compare response rates for patient experience questionnaires and levels of participation pre and post implementation of the toolkit in order to investigate the impact of the toolkit for widening participation levels in different settings.

##### *Comparing text mining with manual thematic analysis*



In each of the three sites, all narratives from a single month will be selected and traditional thematic analysis performed separately by the qualitative RAs (one working on each care pathway). Results will be then compared to the themes identified by text mining in terms of:

- coverage (have the main themes been identified)
- precision (the rate of relevant themes suggested by the programmes).

Given that text mining assigns confidence to the extracted themes, we will explore a useful cut-off that provides an optimal number of themes with good coverage and precision. The findings will be compared across the 3 sites.

We will compare the time needed to perform thematic analyses manually with the text mining. This requires consideration because text mining is done semi-automatically; whereby the themes generated by text mining are then refined by the professionals through (further) inspection and interaction with the data. This can be used to assess the resources needed and will form part of the health economics analysis.

#### *Economic evaluation*

We will ask participants in the interviews and focus groups in WS 4 to complete short surveys about the time spent on providing/collecting/analysing the data. The data from the interviews, focus groups and ethnographic study in WS1, 3 & 4 will be used to develop vignettes of the experiences of people in providing and using data in real-time (eg how it is provided, time spent, perceptions of usefulness). Local finance data will be used to estimate the unit costs of the time and resources. These will be supplemented by national costs where necessary to estimate the overall costs of providing and using the toolkit (bottom up costing method) for each vignette. We will compare the vignettes to better understand variations in the time and resources required to use the toolkit in practice and possible short term impacts of the toolkit on the demand for and use of services and the need for organisational change.

We will also use the vignettes to explore which variables may be important to include in any subsequent clinical trial of the toolkit. These may include the characteristics of the service users and the organisations providing care that could affect subsequent costs and health benefits, the range of services used and associated costs.

### 3. Mechanisms

The multiple data sources above will be used to explore impact of the toolkit on service change, and the mechanisms by which impact occurs.

Observational methods will be particularly important, and will include:

- attending key meetings where patient experience data are discussed
- documentary analysis of reports on patient experience and their use

We will spend at least 4 half days in each site observing toolkit use. We will record field notes based on observation of how staff collect and use patient experience data. Application of theoretical frameworks (NPT and absorptive capacity) in analysis will enable understanding of the mechanisms underpinning change following implementation.

Deliverables: 1. An online toolkit to enable other health service providers to adopt strategies assessed 2. Summary (for NHS managers and commissioners) on the immediate costs and impact of strategies for collecting and interpreting data to achieve service improvement. 3. Public engagement workshop, 4. Conference presentation, 5. Peer reviewed publications x 4, 6. Final report to HS&DR.

## Design and theoretical/conceptual framework:

### WS1 & 3

We will adopt an Experience-Based Design approach (EBD; Bate & Robert, 2006), combining research and insights from our PPI group, to co-design ways to enable and support digital data capture of both quantitative and narrative data and to enable better methods of interpreting and summarising narrative data alongside quantitative data. Experience-Based Design places user experiences at the centre of design and has been commonly used for service improvement, and has become extremely popular as a method for improving NHS services (EBCD). However, there are many variations of approaches that place user experience and user involvement at the centre of research where there is an element of designing an intervention. For example, participatory design and action research approaches have similar goals and techniques. EBD has also been commonly used within computer science and engineering where there is a goal to design new technologies. In this project we are adopting elements of the Experience Based Design approach (EBD), in terms of placing user experience at the centre of designing a toolkit for evaluation. We also draw on multiple techniques of interviews and focus groups to elicit experience. However, this project is not solely a service improvement project, because it is focussing on designing new tools for collecting and using patient experience data.

### WS2

This work stream uses computer science modelling, based on linguistics, statistical and machine-learning techniques, to automatically identify topics and themes and facilitate content analysis.

### WS4

We will conduct a process evaluation qualitative process evaluation, focusing on underlying processes and mechanisms influencing the adoption and use of the toolkit. This is an accepted method for testing fidelity and quality of implementation for complex interventions, and is also in line with the new MRC guidance on process evaluation (Moore et al, 2015)

In specifying causal assumptions as part of the process evaluation, we will draw on Normalisation Process Theory (NPT), which has been applied to implementation in varied healthcare contexts (May, 2009). NPT focuses on social practices and interaction and is operationalized via 4 key constructs: *coherence* (meaning and understanding of new technology/ practices); *cognitive participation* (relational work to sustain a community of practice for a new intervention); *collective action*: (operational work to enact new practices); and *reflexive monitoring* (work done to monitor and appraise new practices). We will draw on NPT resources to inform interview questions (NPT toolkit), and to guide the analyses of both patient and professional experiences of the new toolkit for collection and use of patient experience data.

We will also draw on a theory of absorptive capacity (Cohen and Levinthal, 1990) which offers a powerful way to investigate the ability of organisations to acquire and use knowledge, such as customer feedback, with research suggesting that this represents a critical 'dynamic capability' (Zollo and Winter, 2002) observable in effective organisations. In particular, absorptive capacity distinguishes between an organisation's ability to identify/acquire knowledge (here, patient experience data) and its ability to process, interpret and use this knowledge (Piensing, 2013). To date, this approach has been largely neglected in research into healthcare and other public sector organisations, despite the increased pressure on such organisations to pay attention to, learn from and respond to the expectations of patients and other service users (Harvey et al, 2009). So, for instance, it is possible to examine related aspects of absorptive capacity; systems capabilities, through which organisations can more effectively capture and represent rich data on patient experience, supplemented by coordination capabilities which share this information with staff and socialisation capabilities whereby staff are able to digest and act upon this knowledge (Van den Bosch et al, 1999).

**Sampling:***WS1 - Service users and carers*

A purposeful maximum variation strategy (Patton, 1990) will be deployed in order to select service users and carers for both conditions; ensuring a mix according to various socio-demographic variables including age, socioeconomic status, locale, gender, and condition severity. We will also aim to sample iteratively so that make up of initial groups and interviewees, and early analysis can feed into further sampling, in order to test out further ideas and in order to seek inclusion of 'hard to reach' participants. However, we will also need to be pragmatic due to the tight time frame, and some potential participants may be too unwell, or may choose not to join.

Final sample size will be contingent on the iterative approach described, but we will aim to recruit approximately 20 service users with SMI and 10 carers of people with SMI via a community mental health team (Carers will be recruited via ReThink Manchester Carers Group). We will recruit approximately 20 patients with musculoskeletal conditions and 10 carers of people with musculoskeletal conditions via outpatient clinics. We will be recruiting less carers than people with the conditions, but this level of recruitment should provide a sufficient number to make for meaningful contributions from carers.

Final sample size for staff will also be contingent on initial recruitment but we aim to recruit approximately 20 from MMHSCT via a community mental health teams and including care co-ordinators, psychiatrists and support workers. A number of IT and managerial staff will also be recruited. Approximately 20 staff (including nurses, doctors and healthcare assistants, and managerial and IT staff) will be recruited via SRFT. We will also recruit primary care staff (including practice nurses, GPs, practice managers and IT managers) from two local practices (approximately 20 in total).

WS3 - Participants will be recruited from those who took part in WS1. Approximately 30 patients/carers will take part in 4 focus groups. Approximately 30 staff will take part in 4 focus groups

*WS4 - Qualitative and health economics components*

Individual qualitative interview or focus group, plus health economics questionnaire with:  
 15 service users with SMI and 5 carers recruited by community MHT  
 15 patients with MSK and 5 carers of people with MSK recruited via outpatients  
 10 patients with SMI recruited via Salford CCG and South Manchester CCG  
 10 patients with MSK recruited via Salford CCG and South Manchester CCG  
 20 staff from the community health team and key roles (IT/patient experience) in MHSC  
 20 staff from rheumatology outpatients and key roles (IT/patient experience) in SRFT  
 20 staff recruited from two primary care practice (Salford CCG and South Manchester CCG)

**Setting/ context:**

The research will be set in Salford Royal Foundation Trust (SRFT), an integrated provider of hospital, community and primary care services, including the University Teaching Trust. The Trust provides local services to the City of Salford and specialist services to Greater Manchester and beyond. SRFT emerged as the top Acute Trust nationally in the In-Patient Survey 2013 and celebrated the best results in the country for the NHS Staff Survey 2013.

Manchester Mental Health and Social Care Trust (MMHSCT) is one of only five mental health and social care NHS organisations in the country offering a wide spectrum of mental health, social care and wellbeing services to meet the needs of adults of working age and older adults in Manchester. The Trust provides inpatient care from sites at North Manchester General Hospital and Wythenshawe Hospital. Six Community Mental Health Teams (CMHTs) based throughout the city which provide assessment, care and support for adults of working age and older adults

with mental health problems.

Each setting currently has varied existing ways of collecting and using narrative data in addition to standard survey and quality data (e.g. free text comments via the website at Salford Royal (SRFT), via Twitter and Facebook, letters to PALs, and audio-visual stories such as the 'patient voices' programme in MMHSCT. SRFT already uses handheld devices for collecting patient experience data in response to structured questions on discharge from hospital, and these are periodically used to capture feedback in outpatient clinics. In addition, patients can enter free text feedback via the SRFT website. In MMHSCT, multiple forms of patient experience data are collected via questionnaires, and there have been initiatives to produce audio-visual stories to capture aspects of experience that are used for staff training and for informing service improvement. There has also been an emphasis on service user representation via a user and carer forum, as well as through a 'dignity walk programme', allowing service users to physically take staff through the experience of receiving care within the trust environment. The trust also invites comments via Twitter and Facebook. Primary care settings vary in approaches taken to capture patient experience in addition to the national General Practice Patient Survey (GPPS), but many do collect additional structured questionnaire data, and invite free text comments.

## Data collection

### *Qualitative data (WS1, WS3 and WS4)*

The majority of data collection for the work streams will be from qualitative focus groups and interviews. Focus groups (FG) are commonly used for an EBD approach because they enable relatively large numbers to be recruited and interactive discussion facilitates lots of ideas to be mapped out for design. They are also useful for enabling discussion of sensitive topics and where participants have specific things in common. We have already used this approach for research projects focused on mental health and user involvement in care planning (EQUIP project), and studies focused on design and use of software applications for supporting people with serious mental illness and musculoskeletal conditions. We also know from that experience that not everyone wishes to take part in a focus group, and may prefer to take part in an individual interview. Interviews also allow for some more in-depth and narrative discussion providing rich data to complement FG data.

**Table -1 to summarise data collection from different partner organisations for WS1, WS3 and WS4**

	SRFT (MSK)			MMHSCT (SMI)			GP Practices Salford CCG			GP Practices South Manchester CCG			Grand Total
	WS1	WS3	WS4	WS1	WS3	WS4	WS1	WS3	WS4	WS1	WS3	WS4	
Staff	20	5	20	20	5	20	10	5	10	10	5	10	60
Patients	20	10	15	20	10	15	0	0	10	0	0	10	90
Carers	10	5	5	10	5	5	0	0	0	0	0	0	30
<b>Total</b>	<b>70</b>			<b>70</b>			<b>40</b>						<b>180</b>

Participants for WS3 and WS4 will be a follow up of the existing participants in WS1.

**Table -2 to summarise data collection using interviews and focus groups for WS1, WS3 and WS4**

Work stream/ participants	Data collection	Total participants	Total focus groups	Total ints
<b>WS1</b>				
Patients/carers SMI	3 x FG (6-8 each, total 20) + 10 ints	30	3	10
Patients/carers (MSK)	3 x FG (6-8 each, total 20) + 10 ints	30	3	10
Staff (mental health team)	2 x FG (6-8, 15 participants) 5 ints	20	2	5
Staff (rheumatology OPD)	2 x FG (6-8, total 15 participants) + 5 ints	20	2	5
Staff (primary care)	2 x FG (5 each, total 10) + 10 ints	20	2	10
	<b>Total</b>	<b>120</b>	<b>16</b>	<b>40</b>
<b>WS3</b>				
Follow-up focus groups with patients/carers in each site (community mental health, MSK outpatients, primary care)			4	
Follow-up FG with staff in each site (community mental health, MSK outpatients, 2 x primary care)			4	
			8	
<b>WS4</b>				
Patients/carers SMI/MSK	2 x FG (6-8, total 15 participants) + 5 ints	20	2	5
Patients/carers (MSK)	2 x FG (6-8, total 15 participants) + 5 ints	20	2	5
Patients primary care	20 individual interviews	20	0	20
Staff (mental health team)	2 x FG (6-8, 15 participants) 5 individual interviews	20	2	5
Staff (rheumatology OPD)	2 x FG (6-8, total 15 participants) + 5 interviews	20	2	5
Staff (primary care)	2 x FG (5 in each, total 10 participants) + 10 interviews	20	2	10
		<b>120</b>	<b>10</b>	<b>50</b>

Additional qualitative data collected in WS4 will comprise field notes, photographs, and key documents relevant to patient experience.

## WS2

This work stream depends on use of available data from within the partner NHS organisations including existing free text comments in response to patient experience surveys, audio files from patient stories, complaints letters, PALs data etc. This will be collated by staff within the Trusts for transfer and we have included costs to cover this.

**WS4**

*Health Economics evaluation* – data for this will come from short surveys about the time spent on providing/collecting/analysing patient experience data with the same population as qualitative analysis.

**Data analysis:***WS1, WS3 & WS4: Qualitative analysis*

Interviews and focus groups will be recorded digitally and transcribed ensuring that the data is anonymised and checked for accuracy. Fieldnotes from observation of meetings and the work of staff in interpreting and using patient experience data will also be typed and stored digitally. Typed field notes and transcripts of interviews and focus groups will be entered into NVIVO (version 10) qualitative data analysis software to support organisation of the data within a central storage unit.

Analysis will draw upon some common techniques of grounded theory approaches (after Glaser and Strauss, 1967) including initial coding of text segments, followed by re-coding and memo writing in order to generate conceptual themes. This process will follow the three step process of a grounded theory comprising: 1 open coding to initially label segments of text; 2 axial coding to look at relationships in the data and between the different codes; 3. Selective coding which enables refinement and coding and development of core conceptual themes. A key step in developing core themes is achieved by a process of constant comparison (Corbin and Strauss, 2008). Themes will be constantly compared within and across cases, paying particular attention to negative cases and possible reasons for differences.

*WS2 – Analysis of patient experience data*

Text mining will be developed in WS2 and implemented to analyse data within WS4. This type of analysis typically involves a combination of computer science modelling (based on linguistics, statistical and machine-learning techniques) to automatically identify main topics and themes and facilitate content analysis. For example, Greenwood et al. (2013) used Naïve Bayes classification to identify sentences from patient blog posts that reference subjective patient experience, with specificity of 72% and sensitivity of 96%. Similarly, in our previous work (Kovačević et al, 2012), we used machine-learning to automatically extract emotions (e.g. hopelessness, thankfulness, anger, fear, etc.) from suicide notes, along with other common information (e.g. instructions, blame, etc.). The first step in this WS will include building an annotated representative sample corpus of 500 patient experience narratives from both participating Trusts, in which we will manually identify mentions of topics, map them to experience categories and assign sentiment polarity and temporal aspect (present, past, current). This corpus will be double-annotated. Two thirds of narratives will be used for lexical and contextual profiling of experience expressions of interest. We will also use this corpus to assess the need for de-identification of narratives and apply our existing technology to automatically replace any potentially identifiable piece of information (e.g. names, professions, emails, etc.). The final third will be used for the evaluation of the text analytics methods.

The methods for automatic topic/concept identification will rely on a combination of rule-based and machine-learning methods. We will apply rule- and dictionary-based keyword extraction methods with flexible matching to identify mentions of recurrent concepts, while machine-learning approaches will be used for automatic term/concept recognition of other topics. Once identified in text, concepts will be mapped to the experience categories using both lexical similarities between concepts and resemblance of the contexts in which the concepts appear.

Concepts will be associated with positive or negative sentiment through a classifier that will be trained on the sample corpus. Temporal context (past, present, future) will be assigned through a previously developed machine-learning approach that has been applied to clinical notes, but will now be retrained in the context of patient narratives.



Clustering will be done by first using text-mining methods to extract mentions of key entities and terms (e.g. treatments, drugs, departments, family members, quality of care, etc.) from feedback data. We will then associate these terms with any negation, opinion and polarity as specified in free text using text-based sentiment mining tools. Along with other linguistic indicators (e.g. verbs, adjectives and adverbs used), we will thus generate a profile for each individual feedback narrative, which will contain key healthcare and quality of life terms, communication references, associated sentiment, main linguistic clues, etc. These profiles will be then used as features for applying different machine-learning methods for clustering both narratives and key healthcare terms into groups of similar entities. Various clustering methods will be explored – in a recent collaboration between Sanders and Nenadic (a jointly supervised MSc project), we have shown that hierarchical clustering showed better results than agglomerative methods when applied to clustering healthcare social media posts. Finally, these clusters will be compared to our initial hypothesised ('standard') themes and those that do not map to expected "dimensions" will be considered as new themes and further qualitatively analysed. We will also apply this methodology to cluster key healthcare terms identified in narratives, as they can also indicate patterns, trends and shifts in text. To apply this in practice, one will apply the same method for profiling narratives in the current month, quantify those to map to standard themes i.e. dimensions and then look at those that do not (reasonably) map to existing ones – so these will be new trends, emerging themes etc.

## Dissemination and projected outputs

The research findings will be published in a range of academic journals, including clinical and health services research journals, as well as specialist economics, informatics and social science publications. We have a track record of high impact publications of policy related research. We will aim to publish in open access journals to maximize circulation, and funds have been requested to ensure this is possible.

We will also use our previous and current experience of dissemination through the NIHR CLAHRC Greater Manchester (Boaden is Director, Hodgson is co-lead for Primary Care, and Lovell is lead for the Patient Experience theme), the Health eResearch Centre (HeRC- Ainsworth is Deputy Director, Dixon and Lewis lead the 'Co-Producing Outcomes' theme, Ainsworth, Nenadic lead 'Informatics' theme), the Manchester Connected Health Ecosystem (Ainsworth, Lewis, Dixon and Sanders are members), and the NIHR Greater Manchester Patient Safety Translational Research Centre (Bower is theme lead for Multimorbidity). These organisations will be used to disseminate an accessible version of the toolkit to a wider audience, including professionals, managers and commissioners, and patients, service users and carers. Materials for online dissemination will be co-produced with our PPI group. We will also produce a video to explain the research and hold a public engagement event for key stakeholders in collaboration with our PPI group. All participants will receive feedback of results from associated workstreams.

Maximising the quality, effectiveness and safety of care for people with long-term physical and mental health problems is a key priority for the NHS, and the research will provide a range of outputs in order to maximise the impact of this research for improving services. In focusing on exemplars in multiple clinical and service domains, the findings will be directly relevant for large populations of patients with physical and mental health conditions, including single conditions but also co-morbidity. We expect the research will also achieve impact beyond these groups of patients and will provide important insights to enhance participation in giving patient experience feedback beyond these specific groups (including other vulnerable groups, and carers for people with other conditions). The use of text mining and innovative approaches to transforming and summarising multiple sources of data will be relevant universally across the NHS.

Outputs will include:

- An interim and end of project report for HS&DR



- Peer reviewed publications in high impact journals
- Conference presentations – academic and service provider events, as well as INVOLVE
- A public engagement workshop event
- A toolkit for other health service providers to adopt strategies to improve collection and use of patient experience data
- Summary (for NHS managers and commissioners) on the immediate costs and impact of strategies for collecting and interpreting data to achieve service improvement.
- Summary of the potential long term impact on the costs and health benefit of services.
- Information about key issues and parameters to design further evaluations as the intervention(s) are developed and standardised.

We will ensure that the process evaluation (see above) gives consideration to generalizability and implementation issues.

Expertise in implementation and the study of implementation will be provided by Boaden, and will draw on wider expertise within CLAHRC GM as appropriate.

We will give consideration to the development of a 'How to, Why to' guide, similar to those produced by the National Technology Adoption Centre (NTAC), or guidance similar to that produced by NICE to support implementation (Boaden is a member of the NICE Implementation Strategy Group). This will be developed from the process evaluation, and included as part of the final toolkit.

We will initially develop links through the network of CLAHRCs across England to identify other areas where this work is likely to be of interest, which is possible through Boaden's role as Director of CLAHRC GM. CLAHRC's own communication mechanisms have national reach, and partnership with the GM AHSN will also enable wider implementation of best practice across sites in Greater Manchester and links to the national network of AHSNs.

We will seek consultation from other Trusts as we develop the toolkit, to ensure it is fit for purpose when rolled more widely. This on-going consultation and dissemination about the work throughout the period of research will also generate interest that will be followed up in disseminating the final toolkit.

The programmes will be made available for other Trusts to use through the recently established UK's Farr Institute of Health Informatics research. The institute is building an online shared space (led by Ainsworth & Nenadic) to allow clinical data analysts to find, share, reuse and download data and analytics toolkits. Each of our components will be described using the meta-data standards to facilitate easy tailoring, adoption and deployment in different NHS settings. This approach has been already successfully used to share and disseminate analytical tools for studying asthma within the STELAR multi-institution consortium (Custovic et al, 2015).

We will also draw on the expertise and leadership positions of members of our Study Steering Committee (SSC) who represent multiple national organisations with additional strong networks for dissemination, including: Imperial College Health Partners, NIHR Northwest London CLAHRC, and the Department of Health Policy Innovation Research Unit (Barlow); Arthritis Research UK Primary Care Centre (Chew-Graham); Institute of Psychiatry, Service User Research Enterprise (Poursanidou); NIHR School for Social Care Research and the Personal Social Services Research Unit (Knapp); Rethink Mental Illness; and National Rheumatoid Arthritis Society (IRAS).

## Plan of investigation and timetable

See attached gantt chart for key stages of the project and section on project management for further detail on planned meetings.

Work streams 1 comprising qualitative research to understand perspectives of staff and patients on collecting and presenting data runs month 1 to month 9. This time period enables initial qualitative findings to feed into iterative co-design of new methods and tools forming crucial components of a toolkit for improving the collection and use of data in work stream 3 (9-12).

Work stream 2 commences at month 6 to month 18 and is closely connected to other streams.

Work stream 4 commences at month 12 and runs for the remaining 12 months of the project. This work stream is an intensive evaluation of new methods of collecting, analyzing and presenting data as developed in work streams 1-3. This time period allows for multiple components of a process evaluation incorporating qualitative research and health economics evaluation.

NIHR Study Steering Committee (SSC) meetings will be conducted at two time points: month 4; and middle of year 2. The Project Management Group (comprising PI, the project manager, work stream leads, clinical leads, PPI representatives and researchers) will meet each month. The PPI advisory group will meet at 3 monthly intervals throughout. Site meetings within each Trust will also be conducted quarterly.

Outputs will be produced at key points throughout the project, including publication of a protocol paper within the first 3 months. Papers will be produced from initial qualitative research and co-design work at month 12. A paper from text mining development work will be produced by month 15. Additional papers (at least 4) will be produced by the end of the project including: 1 on organizational capacity, 1 paper on economic evaluation.

During the final 6 months, we will work in collaboration with our PPI partners in developing a video to summarise the work and to conduct a public engagement event to disseminate the work. These activities will be led by our PPI co-investigators and the PPI advisory group.

## Project management

The PI will be responsible for the overall management and responsibility of the study and delivery of the work streams and outputs. Whilst the PI (Sanders) has extensive research experience and has been responsible for leading workstreams in multiple projects, this will be the first large scale project she will lead as PI. She will receive mentorship in project management from Lewis via monthly meetings. Lewis has extensive experience of leading large and complex programmes and trials within NHS contexts and will offer advice to support routine management and overcoming any risks and barriers to the project.

The principal investigator (PI) will meet weekly with the project manager to discuss day to day management issues for the project. The PI will be responsible for overall leadership, management and outputs of the project, and will keep a log of key milestones to be achieved according to the timetable. A risk register will also be maintained and regularly updated in discussion with the project manager and members of the project team. The PI and project manager will discuss both the timetable and risk register weekly in order to ensure the project runs to time, and risks are mitigated without delay. Tasks and actions will be planned, implemented and reviewed at weekly meeting. In addition, an RF (Daker-White) will assist Sanders in providing micro-management of the qualitative research (WS1 & WS4) and this will ensure the PI has time for overall project management. The PI will be responsible for co-ordination of all project related activities, liaison with the NIHR steering group and reporting to NIHR, working together with 2 full time research associates doing the core qualitative research, and the project manager.

The project manager will be an NHS appointment within SRFT and working alongside the

CLAHRC team, but will also have office space and spend at least one day per week within the Centre for Primary Care at the University of Manchester. This will enable the project manager to work closely with the PI, but also with NHS staff (especially IMT teams, and patient experience leads) at both SRFT and MMHSCT, and with existing project managers for related digital health projects mentioned throughout the proposal (ClinTouch/ Careloop and REMORA). This will ensure essential relationships and learning regarding IT management and integration within NHS systems can be built upon and extended for the current project.

The project management group (PMG) will meet monthly chaired by the principal investigator, and comprising the project manager, the clinical leads (Lewis, Dixon) the work stream leads (Nenadic, Boaden, Hodgson, Bower and Davies), the two PPI applicants (AM Lewis & Sinclair), and the appointed research associates. Progress with milestones, timetable and project risks will be discussed and actions agreed to ensure smooth running and coordination of the project.

Each work stream will hold weekly meetings for all involved in the work stream during its active period, including work stream leaders and appointed research staff. These meetings will also be attended the PI and project manager.

In addition to the above, we will hold quarterly site meetings within SRFT and MMHSCT. In SRFT, these meetings will be attended by the PI, project manager, the clinical lead for MSK care pathway (Dixon), Rachel Georgiou (Associate Director of Research & Development), representative of the IMT team, lead for patient experience. In MMHSCT, these meetings will be attended by the PI, project manager, the clinical lead for SMI pathway (Lewis), lead for patient experience (Cahoon) and Dr Richard Hopkins (consultant psychiatrist in community mental health & lead for mHealth/ eHealth innovations).

Whilst we have suggested multiple and regular meetings for the various work streams, study sites and the PMG, we will use a range of meeting formats including telephone and video conferencing as well as face to face, to ensure attendance of relevant participants.

The PPI advisory group (comprising 10 members, including AM Lewis and Sinclair) will meet quarterly to offer advice and input to coincide with activities of the work streams running at the time of each meeting. These will be attended by the PI and will be led by Daker-White in conjunction with appointed qualitative researchers and PPI applicants (AM Lewis and Sinclair).

We will hold half-day bi-annual meetings for the entire project team to assess progress, share work stream activity and ensure that research and findings are actively disseminated throughout.

The SSC (see page 1) will meet early in the project (month 4), and at 18 months. The team would provide reports for each work stream. The steering group will be able to comment on these reports, feed back to the project team in terms of progress in line with the protocol. The SSC will also be sent the interim project report and the final report for their comments prior to amendment and submission to the NIHR HS&DR Board.

## Approval

Full ethical review will be required for the proposed work and we have commenced the process of applying through the IRAS system (IRAS ID: 191177).

There may be ethical issues associated with disclosure of patients' experiences of care, due to privacy concerns, and worries about potential consequences of any identifiable negative feedback. This is especially important to consider in relation to SMI, where service users often report feeling disempowered. We will build on our established PPI links and the active

involvement of our PPI co-investigators to ensure we maximize engagement and responsiveness to ethical concerns which will be crucial for maximizing participation in providing feedback, and for making overall improvements to collection and use of relevant data.

## Patient and Public Involvement

In advance of this commissioning brief (CB), a PPI collaborator on another project proposed it would be useful to give instant feedback following a consultation with a hospital specialist or GP. That PPI group have provided input and two members have offered to join a new advisory group for this work. One carer member shared frustrations of giving feedback on behalf of a relative, which she later submitted via PALs. She felt that giving feedback should be made easier at the point of service delivery for carers and patients, consistent with the CB. We have also had input from a PPI advisory group of mental health service users who have worked closely with us on a project to develop a mobile phone support system (ClinTouch). Members have often discussed experiences of services and the potential usefulness of providing electronic feedback on services, in addition to reporting outcomes, echoing the CB's point that, compared to methods for measuring patient outcomes, less attention has focused on patient experience. Members of this group have been supportive of this project, feeding directly into the research questions and plans, such as issues concerning anonymity of feedback.

We will form a PPI advisory group of patients, carers and mental health service users (10 people). We will meet quarterly for input on study design, project information resources and outputs. They will have a central role in translating results from the first work stream into design of a new toolkit for improving collection and use of data. Several members of current PPI groups with relevant long-term conditions have already volunteered to join this group, and we have included costs for two members of the PPI advisory group to be PPI co-investigators (INVOLVE rates) to help with research activities, including conducting focus groups. They have extensive experience of working with researchers and some have undertaken research training developed at UoM. This training would be available to other PPI members. Additional volunteers for the PPI advisory group will be recruited from our local PPI group (PRIMER), 'Citizen Scientist' ([www.citizenscientist.org.uk](http://www.citizenscientist.org.uk)) and the Health eResearch Centre (HeRC) PPI group. We have requested funds to reimburse them for their time and travel costs. Our PPI group will also have a central role in summarising and disseminating results, including preparation of a video to explain the work and its a public engagement workshop.

## Expertise and justification of support required

Sanders has expertise in patient/carers experience and qualitative evaluation (including eHealth). She will lead the project and the qualitative research. Lewis is Professor of Psychiatry, academic lead for mental health in MAHSC, NIHR Senior Investigator, and CI for ClinTouch/CareLoop projects. He will provide expertise for SMI and mentorship for Sanders. Dixon is an MRC Clinician Scientist & rheumatologist. He will provide expertise for musculoskeletal conditions and use of secondary care data. Bower has expertise in the General Practice Patient Survey for measuring patient experience, and complex interventions in multimorbidity, mental health, and patient safety. He will provide expertise on intervention development and evaluation (WS3&4). Nenadic is a computer scientist with expertise in text mining. He will lead WS2 and supervise text mining. Daker-White is a sociologist with expertise in qualitative methods and will co-supervise qualitative research. Ainsworth is an expert in health informatics and chair of an eInfrastructure Working Group ([www.farrinstitute.org](http://www.farrinstitute.org)). He will provide expertise on large-scale data sets, mobile computing and data security. Kontopantelis is a senior biostatistician with expertise in computational statistics and large-scale primary care databases. He will provide statistical expertise for WS2. Davies has expertise in cost-effectiveness analysis and will lead on health economics. Boaden is Director of GM CLAHRC. She will lead WS3, add organisational expertise and facilitate linkage with CLAHRC. Hodgson has expertise in organisation and management in healthcare, and the use of knowledge in NHS trusts. He will lead organisational analysis. Lovell

is Professor of Mental Health and NIHR Senior Investigator and will contribute expertise in user involvement and complex interventions in mental health

We are requesting funding for the applicants at the University of Manchester: Sanders (20%), Nenadic (6%) Daker-White, Davies, Kontopantelis, Boaden & Hodgson (2.5%), Lewis (2%), Dixon, Lovell, Ainsworth, Bower (1.5%).

We have requested 2 Research Associates (100%, 21 months) to co-ordinate qualitative research activities, 1 Research Associate (100% 10 months) to work on text mining, 1 Research Associate (40% 12 months) to conduct health economics research, 1 IT software developer (100% 2 months) to make any changes needed to software resources for data collection (e.g. the ClinTouch mobile platform) during the co-design phase (WS3) whilst preparing for evaluation of the toolkit.

We have requested costs for a project manager (NHS post) who will work alongside the CLAHRC team at Salford Royal Hospital (50%), and will also have office space in the Centre for Primary Care (University of Manchester) for 20 months from the start of the project. This will ensure co-ordination and management across the multiple NHS sites and work streams

We have added costs to cover input from NHS technicians in each site to identify sources of data for analysis in WS2, this includes data technicians in each site with supervision from a senior member of their respective IT teams. We have also requested funds for input from Leads for Patient Experience in MMHSCT (Cahoon), and SRFT (2%, Band 8). We require a large team of existing staff in order to support the range of methodological approaches and sectors within this research. Many of the applicants already work together on other grants and within NIHR-funded infrastructure such as CLAHRC and so the resource requested here is in addition to that but will be directed specifically at this work, since relationships and working processes are already well established.

We have also requested funding to cover time for staff participants in each site and thank you vouchers for patients and carers, as well as travel, refreshments and room hire. We have costed time, refreshments and travel for PPI advisory groups members (x10), and for two PPI members (AM Lewis and Sinclair) to be co-investigators in conducting qualitative research (8 days each at INVOLVE rates). We have costed for research team travel, transcription of qualitative data, and digital interface design. For equipment, we have costed for 2 encrypted voice recorders and 3 computers. For dissemination, we have costed for 4 Open Access publications, 4 UK conferences, including INVOLVE, and one international conference. We have also costed for a dissemination engagement event with key stakeholders in the NHS including service users and providers, and for related dissemination materials including a video.

Costs for travel, refreshments and overnight accommodation have been included to enable two study steering committee (SSC) meetings to be conducted with members coming from London, Cambridge, York and Keele. We have also included costs for PPI members of the SSC.

We have included costs to enable 3 members of the research team to attend a start-up meeting in Southampton.

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