National Institute for Health Research

NIHR Research for Patient Benefit (RfPB) Programme

Final Report Form

IMPORTANT

Final reports are required from all projects funded through the NIHR Research for Patient Benefit Programme. The RfPB Programme requires a final report in order to:

- ensure accountability
- aid in appropriate dissemination of project results
- encourage quality assurance of project outputs
- assess the impact of the research supported by the Programme
- demonstrate the achievements of the Programme

Please keep these aims in mind while completing your final report.

The report needs to offer:
a) a clear summary of the project for practitioners and users of research
b) a record of challenges faced and modifications made to the study
c) a description of experience with patient and public involvement that might help identify lessons for future research
d) an impact assessment both locally and for the NHS more broadly
e) a summary of any outputs, such as publications, from the research (which should be updated as outputs occur). Completion of this report should not pre-empt any publications that have been prepared or are in preparation detailing project results.

The views expressed in this report should reflect those of the entire research team.

Following submission and assessment of this form, the final version of the scientific and lay summaries will be displayed on the NIHR CCF website and will be accessible to a wide range of interested parties.

You will be required to submit a final statement of expenditure at the same time as your final report. Please note that the completed final report along with a final statement of expenditure is required prior to release of the final project payment.

For further guidance or information on completion of your final report, please contact the regional Programme Manager at NIHR CCF, using the details below:

Eleanor Garratt
Programme Manager for the South East Coast region
eleanor.garratt@nihr-ccf.org.uk
Telephone number: 0208 843 8050
NIHR CCF help line: 0208 843 8057

NHS
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Note the maximum field sizes shown include both printing and non-printing characters such as spaces and carriage returns.

Reference Number PB-PG-0909-20039

Region South East Coast

Date submitted

For office use

1. Project Details

Project Title*:	An exploration of self-care in chronic low-back disorder from the perspectives of practitioners and patients: a Q methodological study		
NHS Contracting Organisation*:	East Sussex Hospitals NHS Trust		
Project Duration*: (months)	20	Grant Value:	£207,569.00
Start Date:	04 January 2012	Agreed Extension (months):	4
End Date:	05 September 2013	Revised End Date:	05 January 2014

2. Grant Holder's Details

Title*:	Dr		
Surname*:	McCrum	Forename*:	Carol
Department*:	Physiotherapy		
Role in Project*:	Clinical lead, projectdata analysis, dissemination		
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3. Details of the Research Team

Co-applicant 1

Title:	Prof Surname: Moore	Forename: Ann	
Post held:	Director		
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Role in project:	Project manager, project design, data analysis, dissemination		

Co-applicant 2

Title:	Prof Surname: Stenner	Forename: Paul	
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Co-applicant 3

Title:	Dr Surname: Cross	Forename: Vinette	
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Role in project:	Project design, data collection, analysis, dissemination		

Co-applicant 4

Title:	Dr Surname: McGowan	Forename: Janet	
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Co-applicant 5

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Role in project:	review of the literature, data collection, analysis, dissemination		

Co-applicant 6

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Role in project:	Service user, review proposal, ongoing involvement in data analysis and dissemination strategy		

Co-applicant 7

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Organisation:			
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Role in project:	Service user, review proposal, ongoing involvement in data analysis and dissemination strategy		

4. Changes to the Research Team

Please outline any changes that have been made to the research team, including an explanation of why these changes were required.

Not applicable

5. Lay/Plain English Summary*

Please provide a summary of the project, including background, findings and conclusions. It is essential that you make the content of your summary and the implications of your research evident to the lay public. It should avoid technical terms and should be written in an accessible style and emphasise in particular the potential for patient benefit arising from the study.
(Maximum 2,500 characters)

Chronic low back pain is very common and costly in terms of personal impacts, disability, work loss and healthcare expenditure. National guidelines encourage ‘self-management', but a key challenge may arise when if patients and healthcare providers have different views and understandings of self-management. Therefore the Q-methodology was used to identify the viewpoints of patients and healthcare providers.

Q-methodology consists of two parts; 1) a review of the relevant literature and series of discussion groups by patient and healthcare providers to gather accounts related to the topic, and 2) a card-sorting task called Q-sort to capture individual’s personal viewpoints. A total of 60 patients and 60 healthcare providers completed the Q-sort process. The analysis and interpretation of the data was carried out by a team of academic researchers, expert clinicians and patient representatives. Four different viewpoints emerged:

1. "I can change" - a strong psychological approach, needing a lifestyle/mind-set change. This was the largest viewpoint, expressed mainly by healthcare providers but also shared by some patients.

2. "Some things can change"- a strong pragmatic approach guided by accurate information and practical strategies, shared mostly by patients and some healthcare providers.

3. "Not sure what to / can change"- expressed mostly by patients and few healthcare providers, this concerns the uncertainty in medical diagnosis, with the need for ongoing access to healthcare resources and assistance.

4. "The others need to change"- expressed only by patients, this concerns the social stigma and negative perception of low back pain being in a chronic condition, with reliance on health professionals to acknowledge and validate their problem.

The study findings demonstrate a clear basis to provide better understanding of self-management and encourage effective partnership between patients and healthcare providers. This will help healthcare providers to develop a better approach to how self-management can be utilised with patients on individual basis. The delivery of the participant-led knowledge translation conference and presenting the findings at local and national conferences have already shown positive impact from both patients and healthcare providers. The findings will add knowledge to the current evidence, which will contribute in future service development and patient education for better and effective management of chronic low back pain.

6. Keywords*

Please provide up to 8 keywords that relate to the research undertaken in this study.

Chronic condition
Low back pain
Pain management
Patient involvement
Q methodology
Self-management

7. Summary of Research and Findings*

Please provide a structured summary of the research including background, aims and objectives, methods, key findings, expected impact on the relevant field and conclusions.
(Maximum 10,000 characters)

Background
Chronic low back pain is one of the leading causes of activity limitation and work absence throughout much of the world. It causes an enormous economic burden on individuals, families, communities, healthcare services and businesses. In order to tackle such an epidemic, many clinical guidelines and policies encourage a self-management approach for chronic conditions, including chronic low back pain. However, achieving a successful self-management approach in clinical settings has shown to be more difficult than expected. One of the possible causes of this may be that there are discrepancies on the understanding of self-management amongst healthcare providers and patients. Evidence shows that patients' beliefs, expectations and preferences about treatments for back pain are likely to influence their engagement and adherence to treatment plans. Equally, it has been documented relatively recently that healthcare providers' beliefs and attitudes influence their low back management practices. Yet, little attention has been given to fully understand the effect of this on promoting the patient's self-management approach. Thus, the aim of this study was to explore both patient's and healthcare providers' perspectives of self-management of chronic low back pain.

Research Aims
• Explore and identify the range and diversity of patients' and healthcare providers' viewpoints on self-management of chronic low back pain.

• Gain insight into how practitioners can effectively facilitate patients to take an active part in their own care.

• Utilise the emergent viewpoints to improve the quality of the management of chronic low back pain.

• Use research findings to refine local chronic low back pain management strategies.

Methods
Q-methodology overview
Exploring viewpoints on self-management in chronic low back pain from the viewpoints of both patients and healthcare providers required an appropriate methodology designed to allow variability whilst affording rigorous comparison of viewpoints. Q-methodology was chosen as the research design for two reasons; first, the methodology permits participants to express their own personal viewpoint in a structured way (as a Q sort), and second, this structure permits quantitative comparison (by correlating Q sorts and running a by-person Q factor analysis) of the viewpoints of a number of individuals. This enables the identification of shared viewpoints, but also of a number of different shared viewpoints.

There were two phases to the Q-methodology. First, the development of a set of statements of opinion (known as a Q-set) about self-management and chronic low back pain. Statements were drawn from the review of the relevant literature and seven discussion groups with patients of varying levels of chronic disability and healthcare providers representing different professions (e.g. physiotherapists, clinical psychologists, pain consultants, GP, practice managers, etc.). The focus groups were all arranged in the southeast of England. A large pool of statements was generated and reduced to a final set of 60.

The second phase involved a task called Q-sort; participants were asked to sort the Q-set into a distribution reflecting their level of relative agreement or disagreement with each item. 60 patients and 60 healthcare providers completed Q sorts. By-person Q factor analysis of the 120 Q sorts yielded a solution involving 4 clearly interpretable factors (i.e. four groups of Q-sorts within the data were sufficiently intercorrelated to be identifiable as "shared viewpoints"). Interpretation was based on two main sources: the statement rankings typical of each "shared viewpoints", and a qualitative analysis of open-ended comments provided by participants. This resulted in a detailed description of four distinct viewpoints about self-management and chronic low back pain.

Key Findings
The summary of the four viewpoints is as follows:

Viewpoint 1: “I can change” - a personal evolution
This viewpoint was the largest in the study. It was expressed by some patients, but mainly by healthcare providers. The main feature of this perspective was the idea that successful self-management of chronic low back pain involves a significant change of personal ‘mind-set’. The way of thinking influences what individuals do and how they feel, and so to move forward with self-management it is vital to adopt a positive, accepting and mindful attitude. Managing pain is therefore much more than a medical matter. It is about understanding and managing one’s feelings and reactions to a life lived with pain, including the ways in which pain may influence relationships with others (friends, family, and healthcare providers), ability to work, ways of moving, self-esteem and sense of identity. Healthcare providers, for their part, can advise on tools and techniques which aid this process, helping to tailor advice and treatment to individual needs. Good pain management is about healthcare providers helping patients to regain control of their lives by changing their lives to cope better with the pain.

Factor 2: “Some things can change” - practical action guided by accurate information
The second largest viewpoint was shared mostly by patients and some health professionals. The main feature of this viewpoint is that self-management of chronic low back pain requires careful observation of what works and what doesn’t, so that the individuals’ lived can be organised to maximise their capabilities and minimise future flare-ups. According to this problem-based viewpoint, the core of chronic low back pain self-management lies in a well-informed understanding of the practicalities of staying active. This has little or nothing to do with psychotherapy or social relationship management. Psychology and relationships are a different life issue best kept separate from chronic low back pain problems and their solutions.

Factor 3: “Not sure what to / can change” - managing the uncertainty
The third viewpoint was mostly voiced by patients and few healthcare providers. The main focus of this viewpoint is on the uncertainty of how to manage the complex characteristics of chronic low back pain. There is a heavy reliance on the healthcare providers to take an advisory role in the self-management of the back pain. Patients want clarity from the providers and they want to be able to trust the advice they get. They want a thorough examination and proper diagnosis, for instance, and they want an effective ‘tool kit’ and support in using it. They feel that managing their pain is a complex affair that cannot be achieved by the patient alone. They want to touch base with the healthcare providers from time to time, and are reassured when they feel really cared for and empathised with. They want a strong relationship of trust with healthcare providers so that help can be accessed as and when needed.

Factor 4: “The others need to change” - questioning the politics.
This viewpoint was expressed by patients only. A distinctive feature is a concern with how patients like themselves are portrayed and treated in society. Since pain is invisible, they find that others do not necessarily take it seriously or believe them. They want to challenge the damaging perception that they are perhaps avoiding work or playing the system. They also feel the need for expert proof such as medical imaging because it can serve to prove the real existence of the pain. The hope is that this validation might also lead to healthcare treatment that might cure the pain. This perspective holds that patients are entitled to healthcare services in the NHS which should be accessible as and when needed. In the context of cuts to these services, it can sometimes feel as though “self-management” is a way to save on costs. In this context it becomes important to insist upon the rights of patients to treatment and the responsibilities of practitioners’ to provide care. Those expressing this viewpoint first of all want their chronic low back pain to be acknowledged. They feel that self-management should not preclude the search for practical and effective treatments which cure the problem.

Expected impacts
The key findings will provide important information concerning self-management for patients and healthcare providers. This can be used to enhance patient self-management and behaviour change as well as professional training to provide practitioners with a better understanding of how self-management can be best facilitated. In presenting multiple viewpoints the results facilitate reflexive practice in both groups, increasingly possibilities for changes that improve self-management. In long term, this should increase patient's abilities to self-manage and implement changes that can reduce recurrence. This will result in a lesser burden to the healthcare providers by reducing the number of treatments needed to alleviate symptoms during possible recurrences, and facilitate efficient use of healthcare services.

A participant-led knowledge translation conference was organised by the research team to present the findings to the study participants as well as local patients and healthcare providers in the southeast of England. The event provided a measure of validity of the findings. Poster presentations have already been disseminated through local and national conferences which captured good interest from clinicians and academics.

Conclusion
The study provides valuable insights into the diversity, complexity and tensions in viewpoints on self-management of chronic low back pain amongst patients and healthcare providers. Addressing these issues and the resulting differences in expectations on the nature and delivery of care seems essential to accomplish more successful engagement in and accomplishment of self-management. Further research and education is needed for all stakeholders to support the process of achieving effective self-management in chronic low back pain.

8. Changes in the project since initial approval*

Please summarise any changes made to the project as outlined in the original proposal and outline the reasons for these changes. If there were no changes to the original plans, write 'not applicable'. **(Maximum 2,500 characters)**

* Field is mandatory

Aims and objectives:

Not applicable

Research Plan and Methodology:

Not applicable

9. Patient and Public Involvement*

The RfPB Programme is particularly keen to learn from the experiences of research teams regarding patient and public involvement (PPI) and contribution from PPI members involved in the research is encouraged when completing this form. Please provide comment on your experiences with PPI, any changes made and lessons drawn. Please include detail of PPI with dissemination and with trajectory into practice both in the project and beyond. **(Maximum 5,000 characters)**

Patient and public involvement was embedded in every step of the research process, from the development stage prior to RfPB application. The research team was built up early on to ensure that the expertise of the field was covered by appropriately experienced individuals. This included the two patient representatives who were chosen carefully to bring in the patient knowledge and personal experience in the topic. The research team held a steering group regularly throughout the project period to ensure a transparent and in-depth communication amongst the patient representatives and the rest of the research team (academic researchers and clinicians). This allowed the project to fully integrate the knowledge and experiences of patient representatives and academic / clinical expertise.

As for the level of public and patient involvement as study participants, the nature of the research design allowed substantial contribution and input from the patient population. The use of Q-methodology was ideal for the research topic as it placed considerable amount of emphasis on patients' and healthcare providers' involvement in the research and data. During the first phase of the research, a series of focus group comprising of local patients and healthcare practitioners (total number of 12 patients and 16 healthcare providers) were carried out to capture real accounts of self-management in chronic low back pain. Guided by few open-ended questions, the participants were able to discuss freely of their views / feelings / thoughts about the topic. The material gathered from the participants then played a key role in constructing the research instrument (i.e. 60 set of statements for Q-sort). During the finalisation of the statement set, the experiential expertise of the patient representatives has been crucial in refining the statements to ensure this is the case from a patient’s perspective.

The second phase of the Q-methodology (Q sort task) allows the research participants to autonomously define their own personal viewpoint of the research topic by prioritising a prescribed set of statements covering a wide range of dimensions within the topic of self-management in chronic low back pain. The task has no right or wrong responses, as it is purely based on an individual’s own subjective response towards the research topic. The participants (total of 60 patients and 60 healthcare providers) therefore needed to make an active and careful decision to complete the task, hence making each responses of the Q sort task unique to each individual. The collection of these responses was then put into analysis to statistically formulate a collective pattern of responses, or “shared” viewpoints. The research team then carefully interpreted in qualitative manner the viewpoints from the standpoint of academic researchers, clinicians, and patients representatives. This mixture of standpoint has built a robust form of qualitative interpretation, ensuring that the data is not only interpreted from an academic and clinician’s standpoint but also from a patient’s point of view. Frequent communication amongst the research team during this phase has led to a very strong understanding of the vital data provided by the participants and produced a confident interpretation of the findings.

As an extension from the Q-methodology research design, the research team organised a participant-led knowledge translation conference where all the research participants as well as the local patient and healthcare providers were invited to further discuss the main findings (i.e. the viewpoints). The event was structured to encourage the attendees to voice their thoughts during a mixed group discussions on the findings and how this can relate to each individuals (as a patient or healthcare provider). The discussion and insightful feedback on the viewpoints have provided a strong face validity of the research team’s interpretation of the viewpoints. The attendees’ general feedback on the event was also strongly positive; the majority of the attendees expressed that having participated in a discussion where a mixture of patients and healthcare providers openly discussed the topic “outside their consultation setting” was very beneficial, informative, and educational to really understand the standpoint of the two groups.

It is in the nature of the Q methodology approach that patient and healthcare provider participants take an active part throughout the research from the beginning (i.e. focus groups) until the end (i.e. the knowledge translation conference). Their engagement in as a participant was paramount to drive the study forward and generate a meaningful interpretation of the key findings.

10. Next Steps to Patient Benefit*

Please provide comment on the likely implications for practice which may result from the outcomes of this project and the next steps to be taken to ensure patient benefit both locally and more broadly. Steps already taken and planned for the future should be included. While in funding research, RfPB emphasises a 3-5 year trajectory into practice, it is important not to ‘overclaim’ and care should be taken to cover the limitations of the study and any risks associated with implementation. Where the project is a pilot, include details of plans for a definitive study, including the likely funder and timetable for its submission. Please give reasons if there is no plan to go forward to a trial at this stage. **(Maximum 5,000 characters)**

To date, the research team has already taken several steps to disseminate the findings to ensure the implications for practice and patient benefit in both locally and nationally (refer to section 11). One of the main tasks which the team planned to set out was the participant-led knowledge translation conference. The conference was organised locally to invite the participants (from both focus group and Q-sort task participants) and any individuals interested in the topic (including current patients and healthcare providers) to a one-day conference where the findings were presented by the team and openly discussed by the attendees.

The knowledge translation conference was split into three parts: the first part consisted of a quick overview of the project and the summary of the key findings, presented by the research team. The second part consisted of an active discussion group in which mixture of attendees were encourage to discuss how they thought about the key findings (i.e. the viewpoints). The discussion group was purposely set up so that there was a mixture of individuals with chronic low back pain and healthcare providers within each group to openly discuss about their thoughts regarding the viewpoints. Finally, the third part of the conference consisted a summary of the discussion group and suggestions on how the finding can be utilised in the everyday practice. The conference has provided a form of awareness/education for the patients, reflection/training for the healthcare providers, and powerful source of research feedback/validity for the project team.

Prior to the knowledge translation conference, all Q sort participant received a short survey concerning their responses on the four viewpoints and whether these truly reflected their viewpoints of self-management in chronic low back pain. The survey responses will inform the study with the validity of the interpretation of the viewpoints. This information will further strengthen the research key findings by demonstrating a continued involvement by the participant to shape the findings.

The study finding has already been presented at academic and clinical conferences both at locally and nationally; abstract presentations were accepted in two local settings and one national setting. The presentation captured many interests by the conference organisers and the delegates; the best oral presentation award was given at the East Sussex Healthcare NHS Trust Inaugural Scientific Meeting and the poster presentation was shortlisted for best poster presentation at the British Pain Society Annual Scientific Meeting. Further abstract was submitted and accepted for the upcoming Physiotherapy UK conference in October, 2014. The research team is aiming to submit an abstract to an international conference in next available opportunity to ensure wider audience.

The research team is currently in progress of drafting several papers for peer-reviewed academic and clinical journals, in which one of the papers is aimed to be submitted towards the end of July, 2014 and others to follow soon.

Besides dissemination in journal articles and conferences, the research team has set out several plans to organise a training / education events aimed at relevant healthcare providers and patients both locally and nationally. For example, the presentation of the key findings is confirmed for the British Pain Society's Pain Education Special Interest Group Study Day in November, 2014. The training / educational workshop will help cultivate a reflective behaviour or behavioural change amongst patients and healthcare providers to recognise that there are different viewpoints which need to be acknowledged and taken into consideration of the treatment of chronic low back pain.

The nature of research design and the subsequent findings allow the viewpoints to be utilised as a source of "tool" to objectively display an individual's standpoint in self-management of chronic low back pain. The research team is keen to take the findings further forward and develop a "patient reported outcome measures" or "patient checklist" to facilitate clearer communication with both patients and healthcare providers. This form of communication may be used as a "reflective" tool for an individual (i.e. "how do I feel today compared to two months ago") or a form of "positioning" an individual's standpoint (i.e. "I relate very closely to viewpoint 2 [pragmatic approach] so I want to know good exercises to help me with the pain"). This form of "guidance" will encourage both patients and healthcare providers to realise their own viewpoint and decide whether to change that viewpoint (and which direction to change) or not, which will build a strong basis for shared decision making in the management of chronic low back pain. Further investigation is required to develop and test its clinical validity and reliability of such communication tool.

11. Key Presentations and Publications*

Please list here any presentations and publications which have resulted from the work. This should include journal articles, conference proceedings, press releases and all publications in the lay and scientific press, including website links to published articles if appropriate. Items that are forthcoming should also be included. **Please note you are contractually obliged to provide 28 days notification prior to any publication.**

Author (s)	**Title**	**Reference/Further Details**
McCrum, C.A., McGowan, J.F., Stenner, P., Cross, V. Defever, E., Lloyd, P., Poole, R. & Moore, A.P.	Exploring the viewpoints of health professionals and patients on self-management in chronic low back pain: A Q-methodology study	University of Brighton Research Poster Competition (Brighton, February 2014)
McCrum, C.A., McGowan, J.F., Stenner, P., Cross, V. Defever, E., Lloyd, P., Poole, R. & Moore, A.P.	Exploring the viewpoints of health professionals and patients on self-management in chronic low back pain: A Q-methodology study	East Sussex Healthcare NHS Trust Inaugural Scientific Meeting (Eastbourne, April 2014) *Awarded for best oral presentation
McCrum, C.A., McGowan, J.F., Stenner, P., Cross, V. Defever, E., Lloyd, P., Poole, R. & Moore, A.P.	Exploring the perspectives of health professionals and patients on self-management in chronic low back pain: A Q-methodology study	British Pain Society Annual Scientific Meeting (Manchester, May 2014) *Shortlisted for best presented poster award
Stenner, P., Cross, V., McCrum, C.A., McGowan, J.F., Defever, E., Lloyd, P., Poole, R. & Moore, A.P.	Patient and healthcare provider viewpoints on the concepts of self-management in the context of chronic low back pain	Will be submitted to Scocial Science & Medicine (Open Access).
McCrum, C.A., McGowan, J.F., Stenner, P., Cross, V. Defever, E., Lloyd, P., Poole, R. & Moore, A.P.	"Changing myself" vs "Others must change": Q-methodology study exploring viewpoints of self-management in chronic low back pain	Will be presented at Physiotherapy UK (Birmingham, October 2014)
Moore, A.P., Cross, V., Stenner, P., McGowan, J.F., McCrum, C., Defever, E., Lloyd, P, & Poole, R.	The perspectives of patients and healthcare providers on self-management in chronic low back pain: A focus group study	Will be submitted to Physiotherapy, Qualitative Health Research, European Journal of Pain, or Clinical Journal of Pain
Defever, E., Cross V., Stenner, P., McCrum, C., McGowan, J.F., Lloyd, P., Poole, R. & Moore, A.P.	A qualitative synthesis exploring self-management in chronic low back pain	Will be submitted to Physiotherapy, Qualitative Health Research, European Journal of Pain, or Clinical Journal of Pain
To be decided	The knowledge translation: An overview of the perspectives of patients and healthcare providers on self-management in chronic low back pain	Will be submitted to Physiotherapy, Qualitative Health Research, European Journal of Pain, or Clinical Journal of Pain