

[IRAS ID: 277764]

ARC WESSEX PROTOCOL FORM

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Chief Investigator Name, Post, Institution,	Professor Mari Carmen Portillo,
and email address	Professor of Long Term Conditions.
	School of Health Sciences. University
	of Southampton
	M.C.Portillo-Vega@soton.ac.uk
Co-Investigator Names, Posts, Institutions &	Dr Hayden Kirk, Consultant
Sector (e.g. NHS, LA, Third Sector, Commercial, HEI)	Physiotherapist & Clinical Director
	Adults Southampton, Solent NHS
	Trust
	Stephanie Heath, WASP Clinical Lead,
	Royal Bournemouth & Christchurch
	Hospital
	Dr Louise Johnson, WASP Project
	Manager, Royal Bournemouth &
	Christchurch Hospitals
	Christenuren riospitais
	Dr David Kryl, Director, Centre for
	Implementation Science, University of
	Southampton
	Professor Alison Richardson,
	Professor of Cancer Nursing and End
	of Life Care, University of
	Southampton & University Hospital
	Southampton NHS Foundation Trust
	Dr David Culliford, Senior Medical
	Statistician, School of Health
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	Sciences, University of Southampton
	PPI representative from steering
	committee.
Proposed ARC Theme	Long Term Conditions: integrating
•	person centred approaches to
	optimise healthy living
Proposed Research Title: The project title should	Using the Wessex Activation and Self-

state clearly and concisely the proposed research. Any abbreviations should be spelled out in full.	Management (WASP) Tool to design and implement system wide improvements in self-management support for people with long-term conditions.
Proposed Start Date: This should be from the first of the month regardless of whether this is a working day or not.	1 Oct 2019
NOTE: Projects cannot start before 1 Oct 2019.	From April to October 2019, Professor Mari Carmen Portillo and Dr Chris Allen will provide advice on the projects design funded from other sources.
Duration and End Date: (Max 24 months)	19 months (end date: 30 th April 2021 – extended due to COVID-19)
List NIHR ARC Wessex NHS Partners who will collaborate on the research: Institution and Name of Lead Contact	Solent NHS Trust
Cash Amount Requested:	£9,838.00
	Plus, matched funding for staff costs:
	Professor Mari Carmen Portillo (10 %) Dr Chris Allen (20%) Dr David Kryl (5%) Professor Alison Richardson (5%) Dr David Culliford (1%)

Scientific Abstract

The scientific abstract should be a clear and concise scientific summary of the Detailed Research Plan / Methods.

The following is a list of potential elements / headings that might be included in the protocol depending on the design of the proposed research, the setting, and programme being applied to, and whether it is for primary research or evidence synthesis. It will be for applicants to decide the appropriate elements to be included in the scientific abstract and these could include elements outside this list.

Research question
Background
Aims and Objectives
Methods
Timelines for delivery
Anticipated Impact and Dissemination (including lay dissemination opportunities)

Text field - max 500 words

The NHS is looking to achieve better health outcomes, improved experience for service users, and more effective use of services and resources for those with a long-term condition. Self-management support is one of six core components of Embedding Personalised Care, as outlined in the NHS Long Term Plan (2019).

The Wessex Self-management and Activation Project (WASP) has developed and piloted a self-assessment tool, which can help those responsible for the delivery of health and social care to reflect on the way in which they support the personalised care agenda. The WASP Self-Assessment Tool will help teams and services to benchmark how they are performing in relation to best practice principles, and to identify where improvements can be made.

System wide analysis is a unique feature of the tool, as it is designed for completion by service users, frontline practitioners, service managers, organisational leads and Clinical Commissioning Groups. It asks about behaviour - WHAT people *actually* do in relation to enabling self-management support. It also uses the COM-B (Capability, Opportunity, Motivation and Behaviour) change model to understand WHY they do (or don't) exhibit certain behaviours.

Early findings from use of the tool highlighted discrepancies across the system, and in particular between:

- commissioning and management objectives for delivering personalised care, and
- frontline practitioner reported behaviours and patient reported experiences.

The demonstrator sites for the first version of the WASP tool confirmed proof of concept.

The next stage of this work involves use of the self-assessment tool in combination with a training and support programme. This programme consists of a series of online workshops, delivered across a 4 month period. It includes:

- Core training on key elements of the Personalised Care Model (5 x 1 hour sessions)
- Optional webinars covering various enablers of personalised care (6 x optional 1 hour sessions)
- The use of quality improvement methodology, to support healthcare teams (consisting of commissioners, managers, frontline staff and patients) to identify and deliver local, co-produced service improvement projects (5 x 30 minute sessions).

Up until March 2020, the WASP Self-Assessment and subsequent support workshops were are currently being delivered across the Wessex region, with a range of teams providing self-management support and personalised care to people with a range of long-term conditions. Programme delivery was suspended due to COVID-19. The support package has been redesigned, taking into account COVID-19 restrictions, but also feedback and learning from the first round of project teams. The new version of the WASP Support Programme will be delivered remotely over a condensed period, and with a more structured programme.

This project seeks to evaluate this programme of work, to better understand if it works, how it works and how the programme itself can be improved.

The aims of this project are to:

- Examine the use of the WASP Bespoke Support Programme and its role in facilitating improved whole system self-management support in a range of healthcare services.
- Determine the feasibility, acceptability and effectiveness of the WASP Bespoke Support Programme to inform improvement projects in a range of practice settings.
- Explore how each part of the WASP Bespoke Support Programme works and identify areas of the programme that require refinement.
- Better understand the contribution of co-production during implementation of the WASP Bespoke Support Programme.

This project is a qualitative evaluation of an existing programme. It will involve:

Interviews with staff and service users who are taking part on the WASP Programme

Data collected through the interviews will be analysed, to provide an in-depth understanding of the effectiveness of the programme – how it informs improvement across a range of settings, and the role of co-production within this.

Plain English summary

A plain English summary is a clear explanation of your research.

If your application for funding is successful, the summary will be published on the NIHR ARC Wessex Website

A good quality plain English summary providing an easy to read overview of your whole study will help:

- those carrying out the review (reviewers, board and panel members) to have a better understanding of your research proposal
- inform others about your research such as members of the public, health professionals, policy makers and the media

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the research funders to publicise the research that they fund.

If it is felt that your plain English summary would benefit from further review to make it accessible and clear then you may be required to amend it prior to final funding approval.

Content

When writing your plain English summary consider including the following information where appropriate:

- aim(s) of the research
- background to the research
- design and methods used
- patient and public involvement
- dissemination

Text field – max 450 words

The NHS wants to achieve better health outcomes, improved experience for patients, and more effective use of services and resources for people living with a long-term health condition. Helping people to self-manage their condition helps improve people's health and also their experience of managing the condition in everyday life. Increasing people's knowledge, skills and confidence may help them to be more actively involved in self-management of their condition. This is sometimes referred to as 'patient activation'.

The Wessex Activation Self-Management Programme (WASP) Self-Assessment Tool has been developed to help health teams understand where their service could do more to help people be more active in the management of their condition. The tool can be used by people who use services and people who plan, manage and deliver care and services. It asks about behaviour – WHAT people actually do, and WHY they do (or don't do) certain things. The answers can help health teams decide how to improve their service. We have already tested the tool in a number of different services. Early findings show differences across health services. For example, managers reported ways in which their services helped people to be more active in the management of their condition, but frontline staff (such as nurses and doctors) and patients themselves often had different experiences of this.

The next stage of this work has involved using the tool to help project teams (consisting of commissioners, managers, front line staff, and patients and service users) identify aspects of support in their service that require improvement, and help services to make these improvements. This is being done by:

- Assessing the services current practice in relation to self-management support, using the WASP Self-Assessment Tool.
- Providing training and support (over a 4-month period) to enable teams (consisting of those who fund the service, managers, frontline staff and patients themselves) to identify and deliver improvements
- Re-assessing self-management support by repeating the WASP Self-Assessment Tool.

These support workshops are currently being run across the Wessex region, with a range of teams providing self-management support and personalised care to people with a range of long-term conditions. From March 2020, delivery has been via virtual platforms, as a result of COVID-19 restrictions.

This project seeks to evaluate this programme of work. We will do this through qualitative interviews with participants of three teams completing the programme. During the interviews, participants will be given the opportunity to share their experiences of the service in an interview at the start of the project, as well as of the coaching and support that they have received during an interview at the end of the project. This will help us understand how the coaching and support works and how it can be improved upon.

Detailed Research Plan

Using <u>all</u> of the headings in the order presented below, please use this section to clearly explain your proposed research. Schematics, tables, illustrations, graphs, and other types of graphics can be embedded to clarify the research plan.

- 1. Background and Rationale
- 2. Justification for ARC funding, including fit with ARC Wessex strategic aims, and details of plans for cross-ARC collaboration)
- 3. Aims and Objectives
- 4. Research Plan / Methods
- 5. Project / research timetable / GANTT Chart
- 6. Project Management
- 7. Ethics / Regulatory Approvals. Are these required? Has they been obtained?

- 8. Patient and Public Involvement
- 9. Project / Research expertise of team
- 10. Success criteria and potential barriers to proposed work

If appropriate, please include with your research plan copies of any questionnaires or other documents that you have prepared to be used as part of your study.

Background

The provision of healthcare in England, as with much of Europe, is facing increased social and economic pressure, which has largely been brought about through increased longevity and the subsequent shift from an acute to chronic disease profile (Bury and Taylor, 2008). 15 million people in England live with a long-term condition and meeting their needs accounts for as much as 70% of the NHS budget (Department of Health, 2012).

In the pursuit of ensuring more sustainable and holistic models of care, there has been increased attention into how care is thought about, organised and delivered, with an increased focus on people self-managing their condition alongside support from health and social care services, and voluntary organisations (NHS, 2015, 2019). To meet expanding demand and improve the lived experiences of those managing one of more long-term condition, there has been an increased focus on supporting those living with a long-term condition to gain the appropriate knowledge, skills and confidence to self-manage their condition and the impact it has on their day to day life with support from a range of services (Bury and Taylor, 2008). This represents an ideological shift that moves away from seeing patients as passive recipients of care, to active and engaged partners who co-produce their care experience. Alongside this shift, there here has been an increased focus on the delivery of personalised care (Entwistle et al, 2013; 2018); which is a strong driver for increased self-management support, alongside improved health outcomes and the need for demand management strategies to ensure more sustainable use of finite health resources (Bury and Taylor, 2008; Ellis et al, 2017).

Whole systems approach

To date, approaches to self-management support have often reflected a perceived need to mediate patient level deficits in knowledge, skills and motivation. However, evaluations of approaches that target individual behaviours suggest they often merely reinforce existing behaviours, rather than fundamentally changing people's approaches to management (Gately et al, 2007; Kennedy et al, 2007). In addition, research has shown a tendency for healthcare services to impede self-management practices, only tacitly acknowledge people's everyday approaches to management and overlook non-medical priorities (such as social and emotional support) (Been-Dahmen et al, 2015; Entwistle et al, 2018).

Whilst the extent to which professionals are involved in supporting self-management is likely to vary across the population, across conditions and across an illness journey (Boger et al, 2015a; Taylor et al, 2014), there remains a mismatch between the self-management support that is envisioned in policy and that which is delivered in routine clinical practice, across a range of practice settings (Boger et al, 2015b; Gately et al, 2007; Hughes et al, 2018). Such rhetoric extends to use of PAM. For example, a recent survey of clinician attitudes and behaviours towards patients taking on a more active role in the management of their condition, demonstrated considerable variance in the support clinicians offer for patient activation (NHS England, 2015). These findings demonstrated little movement from the attitudes and behaviours seen in an earlier study (Hibbard et al, 2010), despite the increased focus in patient activation.

This is perhaps because in focussing exclusively on eliciting behaviour change at the level of patients, little attention has been paid to the wider landscape of self-management support that these behaviours are nested within. Research has suggested that healthcare professionals face competing clinical priorities, a lack of time in already crowded clinical consultations, a lack of resources, a lack of training around self-management, a lack of confidence and skills, and concerns around professional accountability (Blakeman et al, 2006; Kennedy et al, 2010; 2014; MacDonald et al, 2008). Thus, self-management support is often side-lined. At the level of commissioners, whilst self-management support is conceptually seen as a means through which health can be improved and demand on finite health resources reduced, structural and financial constraints often result in the prioritisation of incentivised clinical outcome measures, over the commissioning of self-management support

(Reidy et al, 2016). Thus, despite the noted importance of self-management, in practice, the resources people need in order to increase their activation and built their self-management behaviours are often difficult to access or indeed entirely absent (Boger et al, 2015b; Hughes et al, 2018). It is increasingly recognised that improving engagement with self-management support requires behaviour change at the level of commissioners, managers, front line staff, as well as patients and their personal networks who have traditionally been the most frequent target of self-management interventions (Taylor et al, 2014).

Awareness of the need for a whole systems approach to self-management is not new. For example, Wagner (1998) identified that even the most activated patients still require access to healthcare services that are configured in ways that facilitate shared care. More recently, the house of care model (Coulter et al, 2013) places an emphasis on a more joined up approach to self-management support, that involves more effective organisational processes and workflows that facilitate positive approaches and greater capacity to support self-management at the level of commissioners, managers, front line staff and those with one or more long-term condition and their carer's. However, the difficulties of implementing and embedding effective whole systems approaches to self-management support into routine clinical practice have been previously noted (Kennedy et al, 2010; Kennedy et al, 2014) and it is clear that the adoption and integration of self-management support requires the adoption of fundamentally new ways of working and a readiness of healthcare services for those accessing their services to take on an enhanced role in the management of their condition (activation 'readiness').

To do this, a deeper understanding of areas where self-management support can be improved in line with best practice guidance in specific healthcare services is required, which will require the input of commissioners, managers, front line staff and patients working together to co-produce solutions and integrate them into routine clinical practice (Batalden, 2016).

Co-production

Alongside an increased focus on patients taking on an increased role in the management of their long-term conditions has been an increased role for patients and public involvement (PPI) in whole systems redesign, with a view to better orientate the provision of self-management support to the needs of people accessing these services. Indeed, effective self-management support that accounts for what people living with one or more long-term condition value is necessarily co-produced between those accessing health and social care and those providing it (Batalden, 2016; Robert et al, 2015). This project seeks to build on recent exemplar uses of co-production (Heaton et al, 2015; 2016; Renedo et al, 2015; 2017; Robert et al, 2015; Wright et al, 2017) both in the design of the research and through recognition of vital knowledge and lived experience of those using health services in shaping future healthcare delivery and whole systems improvement (Batalden, 2016; Robert et al, 2015). It is relevant to explore further the role of co-production in facilitating improved self-management support in a range of services providing care for people with one or more long-term condition.

The Wessex Activation and Self-Management Programme (WASP) Approach

The WASP is led by a Wessex wide network of people from health, social care, commissioning, and third sector backgrounds. The group has a proven record of:

- Producing the first regional guidance for out of hospital rehabilitation, re-ablement and recovery.
- Producing a Wessex PAM guide to support the implementation of the patient activation measure (PAM), with clear examples of how the PAM is being used effectively in Wessex.
- Developing and piloting a self-assessment tool based on the COM-B behavioural analysis framework –
 enabling organisations, services and clinicians to reflect on and assess their current practice in relation to
 the personalised care agenda.
- Actively leading behaviour change through its work with clinical teams and regional sharing good practice
 events.

The WASP approach aims to address one of the challenges of the NHS Long Term Plan (NHS, 2019); the need to adopt ways of working that increase opportunities for improved self-management support and personalised care. To do this, requires a better understanding of current practice behaviours across the system (identifying shared challenges, as well as strengths) in order to offer directions that facilitate change.

The programmes work to date has focussed on the personalisation agenda; in particular, supporting people to manage their health and wellbeing. Previous WASP work streams (listed above) have demonstrated pockets of excellence where clinicians are actively promoting and championing self-management support. However, this work, together with the wider literature (Kennedy et al, 2014), has shown that teams cannot fully thrive without wider system support reflected at scale within organisations, and across broader health and social care systems. Embedding true personalised care and best practice principles of self-management support is not easy, and it is not solely reliant on frontline practitioners and patients.

Like NHS England's (2019) Universal Personalised Care Model, the WASP approach recognises 'whole system alignment' (involving people with lived experience, carers, frontline clinicians, organisation managers and commissioners). WASPs approach aims to understand the behaviour of this system, explore recognised self-management behaviours, and understand the reasons why such behaviours may or may not be performed. Our work draws many parallels with NHS England's (2019) model, with other named components of personalisation (e.g. shared decision making, personalised care and support planning and social prescribing) integrated within our approach as features of personalised, supported self-management.

Previously WASP has created a series of complimentary questionnaires to be used as self-assessment tools to explore behaviours related to self-management support. The tool, which is based on best practice guidance, is designed to be completed by service users, frontline practitioners, service managers, organisational leads and commissioners. It asks about behaviour – WHAT people actually do, in relation to enabling self-management. It uses the COM-B behaviour change model (Michie et al, 2011; 2014) to understand WHY they do (or don't) exhibit certain behaviours. This helps direct *where* and *how* teams can direct efforts to improve and personalise the local services they offer.

This approach acknowledges that some contributors to behaviours lie outside of an individual's control and early findings from use of the tool have highlighted discrepancies across the system, and in particular between:

- Commissioning and management objectives for delivering personalised care and
- Staff reported behaviours and patient reported experiences.

These findings reinforce the findings of previous work (Kennedy et al, 2014) suggesting that self-management support is not wholly reliant on frontline staff and patients and that embedding true personalised care and best practice principles around self-management support is not easy in complex open systems (Thompson et al, 2016). These early findings also highlighted the key role of organisational culture and system support on self-management support.

The WASP team are now using the WASP Self-Assessment Tool in combination with bespoke support workshops to help healthcare teams identify where discrepancies lie, so that improvement plans can be targeted to the real issues. This, it is hoped, may promote a problem-solving approach that supports healthcare teams in better understanding the changes that are needed to support self-management and personalised care in their service.

Whilst the tool can be used for individual reflection, the system wide nature of the tool offers opportunities for wider scale analysis, which it is hoped will help interconnecting parts of the system to understand common challenges and offer directions for *where* and *how* improvement can take place across the system. The integration of the COM-B model enables the WASP tool to offer a tailored approach to solutions based on local findings, recognising that like recipients of self-management support, there is no one-size-fits all approach to systems change. Whilst the demonstrator sites for the WASP tool demonstrated its use in identifying and understanding current system practice around self-management support, there is a need to understand how such learning can be used to support system wide improvement, which is the focus of this research.

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Justification for ARC funding

This project aligns with 2 ARC goals:

- Champion new approaches to personalised care based on evidence. These will result in better health
 and care services which minimise patient effort, reduce waste and expense and can last; and
- Support people to stay healthier for longer and take control of their own health and care.

It also builds on the internationally recognised work of Collaboration for Leadership in Applied Health Research (CLAHRC) Wessex in self-management of long-term conditions and conforms to the Applied Research Collaborations (ARC) objective of Wessex-wide distributed model for research and implementation. Funding from different external sources has been secured and a culture of partnerships between ARC leaders, researchers and Solent NHS trust has already been established to achieve common goals.

In addition, improved personalisation and self-management support are central ambitions of two local Sustainability and Transformation Partnerships (STPs)- Hampshire and the Isle of Wight, and Dorset

Aims and Objectives

This project aims to:

- Examine the use of the WASP Bespoke Support Programme and its role in facilitating improved whole system self-management support in a range of healthcare services.
- Determine the feasibility, acceptability and efficacy of the WASP Bespoke Support Programme to inform improvement projects in a range of practice settings.
- Explore the programmes mechanisms of change and how each part of the programme works, and identify areas requiring refinement.
- Better understand the contribution of co-production during implementation of the WASP Bespoke Support Programme in supporting improved self-management support.

Research Plan / Methods

Design

This project is a qualitative evaluation of an existing programme. It will involve qualitative interviews with people who are participating in the WASP support programme, to better understand how the programme informs improvement across a range of settings, and better understand the role of co-production in this process.

Setting, participants and population

Project teams across the Wessex area have nominated themselves to take part in the programme. These project teams consist of: patients, frontline clinicians (such as doctors, nurses, allied health professionals and health care support workers), managers within organisations, and commissioners supporting people with long-term conditions.

Project teams will represent a collective from one of the following:

- 1. Place-based systems of care
- 2. A defined care/treatment pathway (for diagnosis or symptom focussed support/management) or
- 3. A defined professional group/network working within a geographic boundary.

All the behaviours within the tool are transferable to any setting and population. The existing quality improvement initiative is working with a variety of teams with different clinical focuses and from a range of health care settings

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(e.g. primary care teams, community and acute providers). The existing teams are all in the Wessex area.

Project teams

We anticipate on conducting the qualitative evaluation on 3 of the 14 teams completing the quality improvement programme We intend to recruit members of these 3 teams to participate in pre and post programme interviews.

Project team composition and sample size

Project teams of the existing programme typically consist of at least 1 commissioner, 1 manager, 2 members of front line staff and 2 patients/service users. As part of the existing programme, additional members may attend some stages of the programme, dependent on their specific experiences. This is specific to each project team and will relate to the teams specific focus for improvement, i.e. bringing in people with specific experiences, who may be able to offer unique insights and experiences.

Project teams undergoing the existing quality improvement programme will be invited to take part in a qualitative evaluation. We will select three teams to take part. In these 3 project teams, all members of the core team will be invited to take part in face-to-face qualitative interviews.

We will adopt a pragmatic approach in the selection of these 3 teams, but will aim for maximum variability sampling, by searching for teams delivering care for different conditions and patient groups.

Inclusion criteria

The primary inclusion criteria for the qualitative evaluation (interviews and observations) is:

Professionals or service users who are already participating in the WASP Bespoke Support Programme, and are willing to take part in an interview.

Recruitment

Project teams who are already undertaking the WASP Bespoke Support Programme, will be invited to take part in this research evaluation. The core team will be provided information about the research, and what involvement will consist of. Recruitment of project teams will be staggered for logistical reasons across 3 recruitment stages as shown in **figure 2** below. Currently 14 project teams across the Wessex area have nominated themselves to take part in the programme. We are aiming to recruit 3 of these to the qualitative evaluation.

Data collection, instruments and programme

Pre programme data collection (see figure 1)

Qualitative data collection (at the start of the programme):

Telephone interviews with commissioners (1), managers (1), front line staff (2) and patients (2) from each of the project teams will take place at the start of the programme. Project team members will be encouraged to complete a WASP questionnaire and have a copy of this available for discussion at the interview. This will be used to explore their responses during the interview- particularly around opportunities and barriers to self-management support as per the interview schedule. This will use the individuals completed WASP Self-assessment tool as a heuristic device to discuss experiences of self-management support from different perspectives, as well as the services current self-management support provision as per the semi-structured interview schedule.

Quantitative data collection

Commissioners, managers and front line staff

Commissioners, managers and front line staff will be asked to complete a questionnaire to capture their job

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role/title and years of experience. .

Patients and service users

Patients and service users taking part in the programme will be asked to complete a questionnaire to capture socio-demographic characteristics, such as gender, age, ethnicity, income, education, employment situation, long-term condition(s) and their satisfaction with the service (through a 10 point Likert scale).

Post programme data collection (see figure 1)

Qualitative data collection (at the end of the programme)

Telephone interviews with commissioners (1), managers (1), front line staff (2) and patients (2) from each project team will occur following completion of the programme. Team members taking part in the bespoke support programme will be asked to repeat the WASP questionnaire and bring this with them to the interview. This will only be used to explore their responses in the interview. The post programme interviews will focus on experiences of the support programme, as well as the programme as a whole, in order to gain a more elaborated understanding of how the programme could be refined/improved and rolled out/translated into other practice settings.

In addition, all relevant documentation will be collected for analysis, including copies of the support programmes outputs, such as the implementation of change plan and other outputs of improvement methodologies. A description of the output of all 3 project teams will be developed and clarified with a team representative.

Data analysis

Qualitative data

In depth thematic analysis (Braun and Clarke, 2006) of all data associated with the three project teams recruited to the embedded qualitative study will occur. Analysis will involve movement between viewpoints and theoretical perspectives to gain an in-depth understanding of why and how different stages of the programme did (or didn't) work. As with previous related work, notably Armstrong et al (2015; 2017) and consistent with the iterative approach taken to data collection during the course of the programme, the analysis will involve a constant comparative technique and inductive thematic analysis. This analysis will be supported by NVIVO 12 (QSR International), which will be used primarily to manage and organise the qualitative data.

Qualitative data analysis will occur throughout the programme as part of an iterative and embedded process. The results will be presented in a summary report document, which will be accessible to members of all participating teams and presented at the end of the project, following which, a wider dissemination plan (see section 6 of this protocol) will commence, which will include, but not restricted too disseminated through relevant conferences and publications, within 6 months of the end of the project.

Demographic data will be used to describe the sample who took part, but will not be quantitatively analysed.

Project Management

The WASP group is comprised of the WASP committee and WASP steering group. The WASP Committee is formed by members of the WASP steering group nominated by the committee to perform functions and progress the detail of project plans on behalf of the wider group. The WASP steering group advises the committee. It will help offer strategic direction, ensuring the committee remains accountable for progress against agreed project plans, keeping the direction of project in alignment with WASP principles and expenditure.

The steering group will also actively strengthen and promote links between the project and wider communities, professional bodies and other organisations. The steering group will comprise a range of representatives enabling the project to draw from varying experience and expertise.

The WASP committee has responsibility for progressing the detail and delivery of project plans. The committee

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will provide operational updates to the steering group on a bi-monthly basis. Updates provide detail on the overall performance of the programme and associated items of work

The WASP group (Steering and committee) will work with a number of other groups to support achievement of its stated aims. This may include, but not be limited to the following groups:

- Wessex Clinical Network (NHSE)
- NIHR ARC Wessex
- Health Education England: Wessex
- NHS provider and commissioner organisations
- Social care providers
- Wessex Academic Health Science Network
- Universities
- Health & Social Care voluntary sector organisations
- Local and County authorities

The Wessex committee comprises:

- Chair
- Deputy Chair
- Programme manager
- Finance Lead
- PPI lead
- ARC Long Term conditions theme lead

The Wessex Steering Group comprises:

- Community NHS Provider representative
- Voluntary sector representative
- Acute Trust Representative
- Patient representative
- Clinical Network representative
- Public Health England Representative
- Commissioning Representative

Ethics / Regulatory Approvals

Ethical approval will be sought through the University of Southampton Ethics and Research Governance Committee and the Health Research Authority (HRA) through the Integrated Research Application System (IRAS). Consent will be obtained for members of the 3 project teams involved in the embedded qualitative study. Both the Patient Information Sheet and Consent forms will state that participants can withdraw at any time. Participants can request that their data be removed from the study at any time, all outputs of the project and written materials will be anonymised to protect participant's identity.

This study involves human subjects and includes the data being collected through questionnaires for quantitative analysis, as well as interviews for qualitative analysis. Sensitive personal data will be collected from participating patients, such as gender. It is therefore likely to be deemed as category A research.

Project / Research expertise of team

Professor Mari Carmen Portillo* is the lead of the ARC Long term Conditions theme and has wide research experience in relation to the process of living with long-term conditions. Portillo has led several projects with a special focus on developing and evaluating interventions to improve the integration of long-term conditions in patients' and families' daily lives and validation of measuring instruments. Portillo has been principal investigator of several research projects and initiatives and closely works with third sector representatives regionally,

nationally and at a European level (EUWISE project (7th Framework Programme European Commission, JPND)) in relation to the understanding of systems of supports in the self-management of long-term conditions in deprived areas across Europe and multisectoral action for better living with PD. Portillo has quantitative and qualitative research expertise.

Dr Hayden Kirk is a Consultant Physiotherapist and Clinical Director for Solent Trust's community services in Southampton. As Clinical Director, Hayden is responsible for the clinical care delivered by the 600 staff (medical, nursing and AHP's) across the community and four rehabilitation wards. He sits on the Wessex Clinical Senate (advisory body for NHS England and CCG's) and chairs the Wessex Strategic Clinical Network Community Rehabilitation Group and Trusts Medicines Management Group which developed the WASP process. Hayden's areas of clinical expertise are spasticity management and his research activity has been in community management of spasticity and stroke secondary prevention.

Dr Louise Johnson is a Consultant Therapist in Stroke at Royal Bournemouth Hospital. She also currently holds an NIHR Clinical Lectureship, for which she is conducting a mixed-methods study into motor learning following stroke. Louise has been involved in the WASP project from the outset.

Steph Heath has 17 years' experience within NHS in a range of roles including Specialist Nursing posts in Multiple Sclerosis and Transient Ischaemic Attack (TIA). Personalisation of care and supported self-management has been a central component of both these very different posts (supporting people with self-management across the spectrum of a complex, progressive neurological condition from diagnosis through to palliative care, and in proactive support to reduce risk of future vascular events post TIA). Steph has an MSc in Advanced Clinical Practice focused on reviewing evidence in relation to the use of Patient Activation Measure in TIA and Stroke services.

Anya E de longh is a Senior Self-Management Coach & Primary Care Development Lead, Patient Editor for the BMJ and Subject Matter Expert Associate for Health Education England. Anya is responsible for the strategic and operational service development, leading integration and co-location with primary care and other partners. This includes providing subject matter expertise for quality assurance, national policy and best practice, leading training development within the service and wider systems workforce. She has been involved in providing one to one coaching and group support for as a self-management coach for over 5 years.

Dr David Kryl is the Director of Insight, Wessex AHSN and the Centre for Implementation Science at the University of Southampton. He is the lead for implementation in NIHR ARC Wessex. He is responsible for overall team strategy and the delivery of evaluation and implementation support to both AHSN and external innovation projects. He believes that data, evaluation and insight can improve patient outcomes and are key to making a positive impact on everyone's health and wellbeing.

Professor Alison Richardson is Professor of Cancer Nursing & End of Life Care at the University of Southampton and University Hospital Southampton NHS Foundation Trust and Director of NIHR ARC Wessex. Richardson is an experienced applied health researcher and conducted several large scale evaluations designed to enhance patient outcomes through the application of self-management support.

**Prior to October 2019 (see Gantt chart), Professor Mari Carmen Portillo and Dr Chris Allen will provide advice on study design funded from other sources.

Please describe how patients and the public have been involved in developing this proposal.

Describe who has been involved and why this is appropriate, what role(s) they have played and what influence or change has happened as a result of their involvement.

The WASP tool was initially developed to assess the behaviours of clinicians and managers against best practice guidelines for supporting self-management and the personalisation of care in long-term conditions.

The questionnaire that makes up this tool, was refined using a consensus method, which involved staff with clinical and management expertise in this field and patients with lived experience. The tool was then piloted with patients, clinicians and managers using a 'think aloud' approach (Fonteyn et al, 1993) to ascertain usability from the perspective of all three groups.

Patient and public involvement (PPI) supported the development of this proposal in a number of ways. The project has been discussed with PPI members of the WASP steering group and this proposal has been reviewed by a PPI representative who provided comments on drafts, which has been incorporated into this proposal.

In addition, in the proposed research, PPI involvement in the project teams is essential. Patients with lived experience of using the services of project teams will be able to contribute through participation in the WASP Bespoke Support Package workshops as participants in the project teams: Patient representatives will be identified during usual care received at NHS services directly related to the corresponding project team. We will work with local teams to identify the best opportunities for approaching patients during usual clinical care within the data collection windows. Depending on the nature of the team studied this may occur in a range of settings (clinic-based, home environment, community or impatient settings).

We will ensure project teams include PPI representatives in their workshops/project teams and use their expertise of lived experience to co-produce/design solutions/interventions within their change plan. Teams may include PPI representatives in their teams in the following ways:

- 1. As PPI representatives from Workshop One onwards
- 2. Recruiting PPI representatives with more specific expertise and live-experience most pertinent to the focus of their improvement plan following Workshop Two.
- 3. A hybrid of options 1 and 2.

WASP Steering Group PPI Representation

There will be active representation of PPI in the WASP steering group, which will involve at least 2 PPI representatives. PPI will support with the ongoing focus of the research, for example in providing feedback and supporting with patient facing materials, including recruitment materials such as participant information sheets and consent forms, planning dissemination and all other research related decisions during the projects duration. Contribution to the research phase will be secured as soon as feasible and will be sourced and invited to contribute through the ARC PPI Lead, Caroline Barker.

INVOLVE has developed guidance both on how patients and public can be involved http://www.invo.org.uk/posttypepublication/involve-briefing-notes-for-researchers/ and the processes, procedures and values necessary to support this involvement www.invo.org.uk

Patients and public can be involved in every stage of a research project, from developing a proposal through to dissemination and evaluation.

In your description, you will need to say who has already been and will be involved in your research and why.

Explain why your approach to public and patient involvement is appropriate for this proposal

Describe how you will support and enable patient and public involvement in your research (e.g., payments, training).

Text field – 350 words

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Effective self-management support that accounts for what people living with one or more long-term condition is necessarily co-produced between those accessing health and social care and those providing it (Batalden, 2016). Thus, PPI and co-production is a cornerstone of this project. PPI have been consulted in relation to the creation of the WASP Self-Assessment Tool and have been consulted in relation to the proposed research.

Co-production will continue with PPI involvement in bespoke support programme, analysis of the findings and contribution with dissemination.

The project committee will seek advice from the ARC PPI Lead, Caroline Barker about best use of the CLAHRC-established patient, carer and public led advisory group (WISeRD) and the Wessex-wide Public Involvement Network (PIN) group in the further design and conduct of all aspects of the study.

All those involved in PPI will be compensated for their contribution for all activities in line with INVOLVE guidelines and a specific budget is provided for this. In addition, there is a provision for travel costs to be reimbursed and for refreshments to be provided during the support programme workshops. Participants will have access to the necessary training, delivered through the ARC.

Please describe proposed routes to dissemination, outputs and potential impacts., including plans to submit further applications for research funding.

Text field - based on equivalent fields 500 words

Routes to dissemination

Several methods will be used to ensure the findings of the study are appropriately disseminated to the participating project teams, providers of health and social care services for those with one or more long-term condition in the Wessex area, nationally and internationally in oral (such as conference presentations, workshops and stakeholder events) and written forms (such as a full report and summary report for distribution to participating teams, organisations and commissioners, relevant open access journal publications such as Health Expectations, Millbank Quarterly, Implementation Science, British Medical Journal Open Quality, and blogs providing ongoing information about the project). The project, including its results will be actively publicised through other ARCs, the Academic Health Science Networks (AHSN) and the national NHS England team responsible for personalised care.

To ensure participants and those interested in the study, who did not take part in the bespoke support programme, wider dissemination is planned to include a study blog, active dissemination through ARC and WASP social media accounts and a newsletter, through which interested parties can sign up for updates on the study and its findings.

This project constitutes a clear example of implementation of change in practice through research. The impact will be achieved by working with all the project teams with the support of commissioners and team managers. Furthermore, this project is funded and supported by a range of stakeholders, whose involvement in the project will continue and extend during the life of the project, with the potential for new collaborations and partnerships to emerge.

Outputs

The project will support the integration of the findings into the development of a formal implementation toolkit and guidance for wider teams to adopt the WASP Bespoke Support Programme, to be used alongside the WASP Self-Assessment tool, to inform service improvement across a range of services.

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The findings will help ensure that the future programme is suitably robust, reproducible and effective enough to be tested in a later cluster randomised control trial. Funding will be sought through the NIHR Health Services and Delivery Research (HSDR) stream. It is hoped that in the future, this project will lead to a clinical doctoral fellowship funding application.

It is anticipated that the WASP Self-Assessment tool will be digitalised and a specific budget has been provided for this. This will involve the development of a digital platform that will work at scale to collect, collate, analyse data and produce a digitally generated report and other products to aid dissemination.

Please describe how the project team will work with the ARC Wessex Implementation Lead to ensure findings can be taken up in practice.

Text field - based on equivalent fields 350 words

The ARC Implementation Lead will be sighted on, and contribute to, the research protocol from the onset. This will ensure that practicalities, such as meeting defined evidence requirements, approval pathways and regulations are considered.

By working closely with the WASP Committee, the Implementation Lead will identify appropriate framework(s), testing assumptions and parameters to be considered during evaluation. As this is a non-technology based process change, a focus on routinisation and sustainability is likely to be the most effective route into the NHS. Collecting data on the 10 factors described by the NHS III Sustainability model; preparing the research phase contributors for a possible role as implementation champions; and capturing their drivers for change (GIRFT, QOF, etc...) will need to be considered.

With the Implementation Lead, ARC clinical academics will identify system-level implementation partners such as Wessex AHSN, Clinical Networks (NHSE and Wessex HEE), STP/ICS and Clinical Commissioning Groups, potentially through quality improvement or innovation programmes.

Please detail how the project will contribute to the ARC Wessex research capacity building strategic objectives.

Text field - based on equivalent fields 350 words

To date, the WASP team leads have not been formally research active. They are keen to learn about the methods for developing and executing a formal research proposal at this stage and the applied research process.

This matches the ARC Wessex objective of getting health and care organisations to partner in planning, conduct and implementation of research projects. As well, the team covers two Wessex health systems (Hampshire and Dorset) which further contributes to regional capacity building.

In addition, it is anticipated that through strengthening the collaborative partnership between the university and practice settings (NHS Solent Trust), opportunities to develop individuals in clinical academic roles may emerge. This aligns with Health Education England's (HEE) commitments to ensure opportunities for Health Care Professionals (HCPs) to develop research skills (HEE, 2015), as well as the mandate of central government to develop a healthcare workforce that embraces opportunities through research and innovation to meet the

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increasingly complex and changing needs of those accessing healthcare (Department of Health & Social Care, 2019).

The project as a whole promotes close collaboration between researchers, commissioners, NHS managers, front line NHS staff, patients and the public. It is anticipated that this co-production of knowledge may overcome barriers to knowledge translation and it is hoped that the co-produced knowledge generated through the programme, might bring about innovative ideas that provide opportunities for new collaborative opportunities between the university and a range of practice settings to emerge. It is hoped that in the future, this project could lead to a clinical doctoral fellowship funding application.

Furthermore, the postdoctoral projection of Dr Allen who is actively involved in this project will be guaranteed in terms of understanding, developing his postdoctoral research profile, implementation of research, and creating strong networks at strategic and research levels with important stakeholders from clinical, education and policy settings.

Section 9: Summary of Budget

Please attach the ARC detailed budget form

COSTS IN THE PROJECT NOT TO BE FUNDED BY ARC (<u>CASH BELOW</u>)		
Cost Information	15 Months (£)	Total (£)
NHS funded-contract based posts Programme clinical lead (0.8 fte) Programme manager (0.5 fte) Digital lead (0.1 fte) Site leads (0.8 fte) Specialist trainers (£200 per day, per team (12~4 of which are outside of the research project))	£43,722.00 £30,491.40 £10,505.28 £48,786.24 £2,400.00	£43,722.00 £30,491.40 £10,505.28 £48,786.24 £2,400.00
Consumables Printing and photocopying	£500.00	£500.00
Travel and Subsistence NHS travel to sites	£5,000.00	£5,000.00
Dissemination Costs Sharing event- NHS Conferences- NHS Open access publication- NHS	£4,000.00 £2,000.00 £1,500.00	£4,000.00 £2,000.00 £1,500.00
PPI Costs for programme: (includes £25 per attendance at 7 x team meetings from month 3 onwards- estimated 4 PPI reps per team per meeting, 20 miles estimate return trip millage, 28 x £20 carer support costs for attending meetings)	£11,984.00	£11,984.00
Other Digital tool development (design and development of digital platform to collect, collate, analyse the data, and produce an digitally generated report and other products e.g. slides to add dissemination)	£50,000.00	£50,000.00
Training for WASP team TOTAL	£3,671.88 £214,560.8	£3,671.88 £214,560.8

$\textbf{C} \textbf{OSTS} \textbf{ OF THE PROJECT.} \ \underline{\textbf{FUNDING}} \textbf{ REQUESTED FROM } \underline{\textbf{ARC}}$

Cost Information	15 Months (£)	Total (£)
Consumables		
Printing and photocopying	£200.00	£200.00
Refreshments	£200.00	£200.00
Transcription (£1.80 per min) (36X60-min interviews)	£3,888.00	£3,888.00
Patient Activation Measure (PAM) licenses (£0.50 per patient x 400 x 2).	£400.00	£400.00
Equipment		
Voice recorder- Sony ICD-SX733 4GB Professional voice recorder	£150.00	£150.00
Travel and Subsistence		
ARC travel to sites	£1,000.00	£1,000.00
Dissemination Costs		
Conferences- ARC	£2,000.00	£2,000.0
Open access publication- ARC	£2,000.00	£2,000.00

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TOTAL 9.838.00 9.838.00

Section 10: Committed Co-Funding from collaborating organisations Budget

Please detail cash and/or in kind equivalent commitments per organisation

IN-KIND COMMITMENTS		
<u>Organisation</u>	15 Months (£)	Total (£)
University of Southampton	Prof Mari Carmen Portillo (10%) Dr Chris Allen (20%) Dr David Kryl (5%) Prof Alison Richardson (5%) Dr David Culliford (1%)	
Solent NHS trust	Hayden Kirk (0.05%) (£6,250)	
	TOTAL	
CACH		

CASH 15 Months (£) **Organisation** Total (£) Southampton CCG £6,000 £6,000 Fareham and Gosport CCG £25,000 £25,000 Solent NHS Trust £10,000 £10,000 NHS England £19,500 £19,500 **Dorset CCG** £100,000 £100,000 Fareham and Gosport CCG £60,000 £60,000 TOTAL £220,500

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Appendix 1: The programme: The WASP Bespoke Support Programme

The WASP Support Programme is a 4-month programme of support, offered to project teams across the Wessex region. The focus of the programme is to understand current 'system' practice and behaviours related to personalised care and self-management, providing project teams support to apply quality improvement methodology to address learning from local report findings and coaching to support behaviour change within the local system.

The 'WASP Bespoke Support Programme' has 4 stages – employing 'RAID' (Review, Agree, Implement, Demonstrate) methodology (Rogers, 2006). The RAID approach is well utilised within NHS services as it is considered an appropriate "bottom-up" approach to delivering organisational change via service improvement. The integration of the WASP self-assessment tool within the early review stage provides opportunity for the tool to provide an assessment of where the team is now and help them identify need for and create a case for change. The "Review" stage focuses upon understanding of the current service and analysing performance, behaviours and experience relating to this. "Agree" ensures that all staff within the project team and stakeholders is in consensus regarding the need to change, collaborate and commit to a self-designed/co-designed change plan. The "Implementation" stage sees the change delivered in practice. Finally, "Demonstration" measures and evaluates the impact of the change. The RAID process can be applied cyclically with lessons from the process informing the next cycle of testing/measurement. An overview of these stages can be seen in **figure 3**

WASP Site Leads and Facilitators meet the following specifications.

- Knowledge of Quality Improvement methodology and experience of quality improvement in practice
- Experience of team facilitation
- Teaching and presenting experience
- Clinical experience of delivering personalised care
- Experience of facilitating PPI and co-production

WASP Site Leads and Facilitators are required to attend a training session outlining the schedule of support, delivery methods and support expectations to offer a standardised and consistent site support across participating teams. A specific budget has been provided for this and a provider of the training has been identified.

Stage 1 (Establish Team & Review):

Aims of Phase 1 (Pre-Programme):

- To establish the project team and agree local team lead(s)
- To introduce WASP Site Lead (facilitator)
- To establish ground rules of project working
- To agree methods and timeframe for baseline data collection

Baseline Data Collection:

• To undertake baseline data collection including WASP self-assessment tool over a 1-2 month data collection window (all versions of WASP self-assessment tool).

Dissemination of baseline findings:

To generate a report for the project team with collated responses to the WASP self-assessment tool.

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- To circulate the report in advance of commencing the formal support programme, to provide maximum
 opportunity for team to engage with the report, absorb the detail and generate ideas in advance of the
 next team workshop.
- To ensure team members are aware of the planned approach for the support programme.

Stage 2 (Agree):

Aims of Stage 2

- Teams to develop their knowledge regarding the key components of the Personalised Care Model;
 and to relate this to their WASP Self-Assessment findings.
- Teams to generate and discuss change ideas
- Integration of Model for Improvement with idea generation
- To promote team ownership of the change process
- To support whole-team active participation
- To enable team agreement on focus/goal of their change plan and next steps

Week-One:

- 1: An introduction to the Personalised Care Model.
- 2: Discussion of the results of baseline data collection
- 3: Discussion about of the Model for Improvement and future sessions.

Stage 3 (Implement):

Aims to Stage 3:

- Teams to broaden their knowledge of the key components of the Personalised Care Model, and relte this to their own service and WASP Self-Assessment findings.
- Facilitators will support team members to plan, progress and implement the proposed change working
- Plans will consider stakeholder analysis and engagement
- Teams should include other measures to explore the impact of change plan (e.g. process measures, outcome measures, balancing measures as applicable)

Week 2-5

Between weeks 2-5, project teams will come together to participate in training and facilitated weekly virtual workshops. These workshops aim to facilitate change, using rapid improvement methodology. Each workshop consists of two parts:

- 1. Training on a core element of the Personalised Care Model.
- 2. Support to implement quality improvement methodology.

Week 6-12

In week 6, 11 and 12, project teams will participate in action learning sessions, during which the WASP site lead will use solutions focused coaching (e.g OSKAR coaching model) to support progress of outcomes and proactive problem solving (e.g. both short team focus for each workshop and longer term focus on project progression/outcomes outcomes).

During weeks 7-10, optional addition webinars will be available, covering specific enablers related to personalised care.

OSKAR Coaching Model	Application in Workshops 3-6:
Outcome	Focus upon short and longer term aspirations and goals of project team
Scaling	Acknowledging/quantifying scale of progress towards delivering project goals and achievement of agreed outcomes
Know-how	Exploring and establishing knowledge, resources, expertise required/available to draw upon to achieve outcomes Exploring learning to date/translating learning from other experiences to benefit project progress
Affirm & Actions	Positive reinforcement/recognition of team efforts toward improvement/team strengths/achievements to draw upon Team determined actions to progress project in the next steps
Review (cyclical process	Reviewing progress against agreed actions
therefore Review stage links to next session)	Solutions focused enquiry regarding actions to progress project (what can you learn, what made it better, how could this be even
,	better?)

Stage 4 (Demonstrate)

Aims for Stage 4 (Post-Programme):

- Repeat WASP self-assessment tool (all versions) over a one month data collection period
- The Patient version of the WASP tool will be implemented within usual care consultations during this period to enable patients to complete assessment based on current care experiences.
- Results will be grouped and analysis will include comparisons made with baseline dataset.
- Results will be presented in a report document and presented to the project team in an end of project sharing event.

General:

- WASP sessions are delivered remotely, using Microsoft Teams.
- Each session has a detailed scheme of work and resources, which ensures consistency between WASP facilitators.
- Core sessions last for 90 mins; 60 minutes allocated to training, and 30 minutes allocated to quality improvement coaching.

- Optional sessions last for 45-60 mins.
- See Figure 3 for the programme overview.

Figure 3. WASP Support Programme Schedule



