Safe Care for Adults with Complex Health Needs
Priority Setting Partnership
Protocol v4

This protocol sets out the aims, objectives and commitments of the Safe Care for Adults with Complex Health Needs Priority Setting Partnership (PSP) and the roles and responsibilities of those taking part. This protocol will be kept under review by the PSP Steering Group.

This PSP is led by the National Institute for Health Research Imperial Patient Safety Translational Research Centre (Imperial PSTRC) with guidance and support from the James Lind Alliance (JLA) and the advice of a Steering Group which meets regularly throughout the project.

1. Background

1.1 Background to the James Lind Alliance
The National Institute for Health Research (NIHR – www.nihr.ac.uk) funds the infrastructure of the JLA to oversee the processes for priority setting partnerships, based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), University of Southampton.

A PSP is the process whereby patients, carers, doctors, nurses and allied health professionals to agree what are the most important uncertainties in a particular area (e.g. a disease or a service), in order to influence the prioritisation of future research in that area. The JLA defines an uncertainty as a question which cannot be answered by existing research.

The JLA priority setting method is flexible and responsive to the needs and contexts of different groups, while maintaining the following integral features across JLA PSPs:

- the principle of inclusivity, with patients, carers and healthcare staff working together as equal partners
- methodological transparency
- the declaration of interests
- a commitment to using and contributing to the evidence base

1.2 Background to the NIHR Imperial Patient Safety Translational Research Centre (Imperial PSTRC)
The Imperial PSTRC is a partnership between Imperial College Healthcare NHS Trust and Imperial College London. It has been funded by the NIHR since 2007 and was awarded a further £7 million grant from NIHR for 5 years from August 2017-July 2022. The Imperial PSTRC carries out research into patient safety that can be translated into healthcare policy and practice in the NHS, and in other healthcare systems.

The team at the Imperial PSTRC works in collaboration with patients, carers and the public; other academic and healthcare institutions; policy makers; and the healthcare industry. The research

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1 The term ‘carers’ includes those family members and friends who provide care for a relative or friend
programme focuses on six themes: safer systems across the continuum of care; partnering with patients for safer care; avoiding deterioration and delays in the care of patients with complex needs; enhancing the safety of medication and technology; improving diagnostic accuracy and decision-making; ensuring value for money in patient safety.

1.3 Background to a PSP in Safe Care for Adults with Complex Health Needs

Patients and their families expect that healthcare will be safe. Those who provide healthcare should be confident that they will be supported by their organisation to provide safe care. Many healthcare providers have a good track record in providing safe care. However, adults continue to be at risk of errors and mistakes in their care, even in those organisations with the best reputations. This harm may impact not only on the patient, but also on their carers, and on healthcare staff.

Adults with complex health needs have more than one illness, disease, condition or disability or are being cared for by more than one healthcare provider (e.g. more than one healthcare team) or in more than one setting (e.g. in hospital and at home).

For example, a person with chest disease may also develop heart disease; a person with dementia may also have mobility problems and depression; a person with schizophrenia may develop diabetes associated with their medication. People may also need care from a range of services, including primary care (GPs and the primary care team), community health services, mental health services, general hospital specialties, palliative care, and nursing home care. Some adults may also need care and support at home (some of which is often provided by family and friends) or in a care home. Their care will evolve over time, typically becoming more complicated as time passes.

Those who provide care need to work together, and with patients and their families, to design and provide the care which will best meet their complex health needs and keep patients safe. The organisations responsible also need systems which enable this to happen, including keeping patients safe when they transfer between teams or move from one organisation to another, making sure that care is safely 'joined up'.

The scope of this PSP will be adults aged 18 years and over. It is recognised that those aged 16 years and over are usually able to be involved in decisions about their healthcare. However, there are a number of specific issues for young people transferring from children’s to adult services, which particularly affect those aged 16 and 17 years of age. These care transitions would be better handled by a separate process which might be considered for a future PSP.

Research in patient safety seeks to prevent or reduce the harm caused by mistakes and errors in care. So far most of the programmes to improve patient safety have focused on hospital care e.g. reducing errors in operating theatres, reducing the spread of infection at hospital, and the care of critically ill patients.

This PSP would inform the research agenda for the broader aspects of patient safety. We want to find out what are the key questions that patients, carers, the public and healthcare staff have about the safe care for adults with complex health needs, to help ensure that research will make a real improvement.
2. Aims and objectives of the PSP for Safe Care for Adults with Complex Health Needs

The objectives are to:

- Work with patients, carers, other members of the public and health care staff to identify priorities for research about safe care for adults with complex health needs
- Check which of these priorities have already been answered by research
- Agree a prioritised list of 10 top research questions
- Widely publicise the results of the PSP
- Take the results to research funding bodies to be considered for as priorities for funding.

In addition the Imperial PSTRC will look to tackle some of the top 10 research questions through existing and future research.

3. Who is involved?

3.1 Steering Group

The PSP for Safe Care for Adults with Complex Health Needs will be led by a Steering Group with the following membership:

Patient, public and carer representatives:
- Sandra Jayacodi (Patient and Public Representative)
- John Laville (Carer Representative)
- Katherine Murphy (Patients Association)
- John Norton (Patient and Public Representative)

Healthcare professional and provider representatives:
- Mark Forshaw (British Psychological Society)
- Rose Gallagher (Royal College of Nursing)
- Ann Jacklin (Independent Consultant Pharmacist)
- Rose Jarvis (Academy of Medical Royal Colleges)
- Susannah Long (British Geriatrics Society)
- Lis Paice (Northwest London Whole Systems Integrated Care)
- Joyce Pinfield (National Care Association)
- Joan Russell (NHS Improvement)
- Jo Watson (Allied Health Professions Federation)

The Steering Group will be supported by:
- Sheila Adam (Imperial PSTRC, PSP Lead)
- Stephanie Archer (Imperial PSTRC, PSP Lead)
- Bryony Dean-Franklin (Imperial PSTRC, PSP Lead)
- Anna Lawrence-Jones (Imperial PSTRC, PSP Co-ordinator)
- Kristina Staley (PSP Information Specialist)
- Catherine White (JLA adviser, Chair of the Steering Group)

The Steering Group members will agree the resources, time and expertise that they will be able to contribute to each stage of the process and will operate according to their Terms of Reference.
3.2 Partners
A wider group of organisations and individuals will be invited to take part in the PSP, from the following groups:
- Users and potential users of healthcare services - patients, carers and relatives and the public
- Healthcare staff from across the NHS.
- Organisations that represent those mentioned in the bullet points above e.g. charities, support groups or Royal Colleges.

It is important that all organisations which can reach and speak for these groups should be invited to be involved in the PSP. The JLA will take responsibility for ensuring the various stakeholder groups are able to contribute to the process.

4. Methodology
The detailed methodology will be agreed by the Steering Group, with the guidance of the JLA. It will be consistent with that established in previous PSPs.

4.1 Identification and invitation of potential partners
The process is dependent on the active participation and contribution of a range of individuals and representative groups. “Partners” are defined as organisations which represent those who receive or provide care for adults with complex health needs and which can promote the survey to their networks. Potential partners will be contacted and informed of the launch and aims of the Safe Care for Adults with Complex Health Needs PSP, and asked to promote the survey (see 4.3).

4.2 Progress to date
The initial stakeholder meeting was held on 25th January 2017. It had several key objectives:
- To welcome and introduce potential partners or potential Steering Group members to the JLA process and this PSP
- To initiate discussion regarding the scope of this PSP
- To identify organisations that should be represented on the PSP’s Steering Group
- To hear from the NIHR Greater Manchester PSTRC on the process with their PSP on Patient Safety and Primary Care, and to share learnings and avoid duplication.

The initial meeting identified key organisations to be invited to join the Steering Group, which met for the first time on 5th April 2017. This proposed that the scope of the PSP should be “Safe Care for Adults with Complex Health Needs”. This was confirmed at the second meeting of the Steering Group on 26th May 2017.

4.3 Identifying research questions
A survey will go out to patients, carers, the public, and healthcare staff asking about what research questions they think are most important in improving the safety of care for adults with complex health needs. The scope of the survey will be made clear.

The survey will be agreed by the Steering Group, which will also decide how it will be distributed and promoted. They will also suggest ways to reach seldom heard groups e.g. those with communication
difficulties and those where English is not their first language. The survey will be open for 12 weeks. Paper copies of the survey will be available, and it will also be available online.

PSPs do not need to obtain ethical approval from the NHS Research Ethics Committee and the Health Research Authority (HRA). Prior to the survey there will be background information and a consent question, so that potential participants can read information before they decide whether to complete the survey and give informed consent.

4.4 Refining questions and uncertainties
Survey results will produce “raw” research questions about safe care for adults with complex health needs from patients, carers, the public and healthcare staff. Similar or duplicate questions will be combined where appropriate and those that are out of scope will be removed. The raw information will be turned in to clear questions that research could answer and which are understood by all.

The existing research literature will be looked at to see to what extent these questions have, or have not, been answered by previous research. Questions that have not been adequately addressed by previous research are considered as true uncertainties and will be collated and recorded in a suitable format agreed by the Steering Group. This work will be undertaken by the PSP Information Specialist.

The Steering Group will agree a list of up to 80 research questions which will be ranked through a second survey: a prioritisation survey.

4.5 Prioritisation – interim and final stages
Patients, carers, the public and healthcare staff will help to rank the list of up to 80 research questions through a prioritisation survey. The Steering Group will then agree a shorter list to go forward to a priority setting workshop.

The face-to-face workshop will use group discussions and facilitated sessions to come to a consensus on the top 10 priorities for research in safe care for adults with complex health needs. The method used for this prioritisation process will be determined by the Steering Group advised by the JLA adviser. Participants will be expected to declare their interests in advance of this meeting.

Findings and research
It is anticipated that the findings of the Safe Care for Adults with Complex Health Needs PSP will be reported to funding and research organisations such as the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), NIHR, as well as the major research funding charities. The Imperial PSTRC will look to tackle some of the research questions through existing and future research.

Steering Group members and other partners are encouraged to promote the top 10 research questions when approaching potential funders, or when allocating funding for research themselves

Publicity
Imperial PSTRC, the Steering Group and partners will be encouraged to publish the findings of the Safe Care for Adults with Complex Health Needs PSP. The JLA will publicise the top 10 and the anonymised raw data submitted in the first survey on its website. Imperial PSTRC will produce a final report and at least one academic paper on behalf of the partnership. However, production of an academic paper would not take precedence over publicising of the top 10 research questions.
4.6 When will the initiative take place?

Start date: 25/01/2017 (Initial stakeholder meeting)
End date: Autumn 2018

Date this protocol was agreed by the Steering Group: August 2017