

DISSEMINATION AND KNOWLEDGE MOBILISATION TOOLKIT

*Patient and Public
Involvement and
Engagement in
Knowledge
Mobilisation*

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INTRODUCTION

This toolkit has been developed by the Link Group, Keele University Impact Accelerator Unit, to support Keele researchers, research students and implementation project coordinators in the transfer of evidence based findings into everyday healthcare practice. Link Group members are increasingly asked to compile routes to disseminating and implementing research and have therefore drawn upon their experience and networks to compile this document. The aim of this toolkit is to signpost towards a strategy of knowledge mobilisation and promotion of innovation.

The idea to produce an implementation and knowledge mobilisation resource originated in response to a roundtable discussion session which took place during the 2017 Research User Group annual event. The day, which was entitled 'Accelerating the impact of our research using Patient and Public Involvement and Engagement,' focussed on the role of Patient and Public Involvement and Engagement (PPIE) in the implementation of research and the mobilisation of knowledge. Delegates were invited to brainstorm ideas around the question: 'How do you think PPIE can contribute more broadly to help get evidence based messages out to the NHS?' Ideas were collected from over 80 attendees including patients, carers, members of the public, academics, knowledge mobilisation research fellows and practitioners, clinicians and PPIE staff and are summarised in this toolkit.



HOW TO USE THIS TOOLKIT

This toolkit is intended as a resource to be used:

- At the initial ideas stage of your research project, to inform your approach
- During your research project, to keep it relevant and on track
- As you move to disseminating your research, to have a wider reach
- As you implement your findings into practice, to promote successful adoption and spread

The resource is intended to act as a guide and is not an exhaustive list.



THE LINK GROUP

The Link Group was established in early 2016 to enable and support meaningful Patient and Public Involvement and Engagement (PPIE) in the implementation of research into healthcare practice. The group aims to facilitate the transfer of knowledge and innovations derived from research projects at the School of Medicine, Keele University, for the benefit of the wider community, nationally and internationally. The School already has an existing Research User Group (RUG) which is made up of over 180 members, each with their own experiences of health conditions such as osteoarthritis, chronic pain, inflammatory arthritis, mental health illness and long term conditions. This “Expertise by Experience” helps to produce high quality, patient centred, relevant healthcare research. The Link Group has been established to take this research forward into the implementation phase.

The Link Group works with the Impact Accelerator Unit to advise and co-produce the approach to PPIE in implementation, accelerating impact with the aim of embedding best research evidence into practice. The Link Group provides a proactive forum for implementation issues in alignment with NIHR INVOLVE PPIE standards, promoting the patient narrative throughout the whole research journey and using networks, skills and experiences to support task and finish groups in the transfer of research findings into practice.

The Link Group brings together members of the patient groups, community groups and NHS organisations. It is made up of members of the RUG, along with patient representatives from Applied Research Collaboration (ARC) West Midlands, members of local Patient and Public Involvement and Engagement groups, an ethics specialist, Community and Voluntary organisation links, people with links to charities and charitable organisations, healthcare staff and carers. Professional, personal and volunteering experiences are combined with knowledge of established networks and healthcare practice, and it is this combination of skills and connections which provides strong guidance to projects in the School’s Impact Accelerator Unit. This achieves a pro-active approach responding to projects and matching skill sets to implementation. As a result, the Link Group now has an array of local, national and international connections with healthcare and patient organisations.

SUMMARY POSTER - THE LINK GROUP

Lay Involvement in Knowledge Mobilisation (LINK project)

Sue Ashby, Katie Tempest, John Haines, Ruth Haines, Krysia Dziedzic
 Research Institute for Primary Care & Health Sciences, Keele University, Keele, Staffordshire, ST5 5BG

"We are the living proof...[the result] must be out there in the field so that as many people as possible are benefiting."
 - Lay member focus group

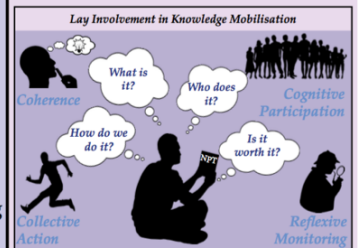
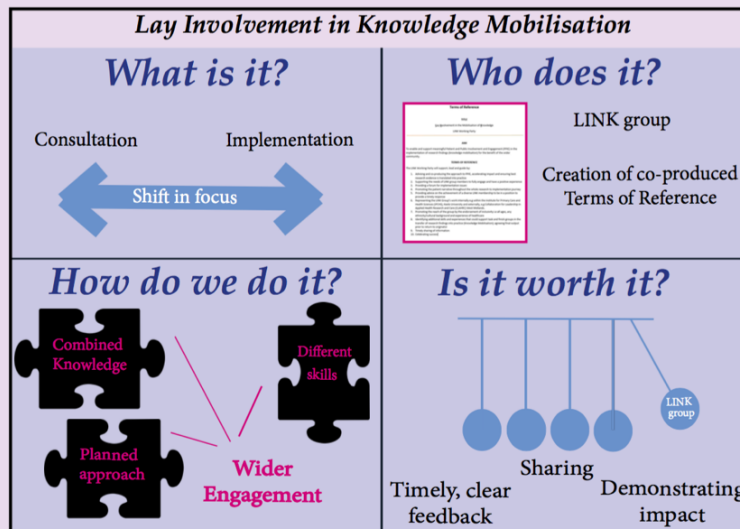
"I don't see how you can have implementation without having the people that it affects."
 - Staff member

Background

Patient and Public Involvement and Engagement (PPIE) in the research process is much more advanced than in implementation



- We investigated the role of Patient and Public Involvement and Engagement (PPIE) in Knowledge Mobilisation.
- A case study design, with 2 embedded cases (Implementation projects) was used.
- Participants: lay members, health care professionals, academics and PPIE coordinators.
- Data collection: 5 observations of knowledge mobilisation meetings, semi structured interviews, (14 participants - 7 lay, 7 staff), 2 lay member focus groups.



Key themes

Potential

Contribution to multi-faceted body of knowledge from differing perspectives; Facilitation of experience and skill sets; Power of collective knowledge

Value of face to face interactions

Proactive approach; Scheduled Task and Finish groups aligned to Impact Accelerator Unit
 Priorities; Knowledge Broker facilitating communication

Influence

Inspiring gatekeepers; Demonstrating what is important to patients

Sharing

Relationship building; Raised profile; Fostering information exchange and ideas about PPIE in implementation

We would like to thank Laura Campbell with her help designing the poster. K Dziedzic is part-funded by a Knowledge Mobilisation Research Fellowship (KMRF-2014-03-002) from the NIHR and the NIHR Collaborations for Leadership in Applied Health Research and Care (CLAHRC) West Midlands. Contact: sa.ashby@keele.ac.uk

Poster presented at the UK Knowledge Mobilisation Forum, March 2018, by Dr. Sue Ashby. Showcasing the research project that investigated the role of PPIE in Knowledge Mobilisation and followed the development of the Link Group.



DISSEMINATION IDEAS

Platforms

Publicity for new innovations and research findings can be targeted at and adapted to various platforms.

These could include; Videos and vlogs; Podcasts; Adverts; GP TV Screens; Leaflets; Email; Radio; NHS Choices; Apps; Websites; Blogs; Infographics; hashtags and social media campaigns; Local and then National TV and Newspapers; YouTube; Poster; Social media e.g. Facebook, Twitter, Instagram; mini Patient information stands in GP practices (similar to Patient Information and Education Resource (PIER) centre at The Haywood Hospital); professional journals; Magazines e.g. parish and community magazines, women's and men's health magazines; Banners; Bookmarks; Business cards; Billboards; Word of Mouth; Post* ; Face to face meetings / presentations to change agents (e.g. practice manager); Professional conferences; National awareness days and campaigns

* It is advised that covering letters are sent out to explain what the innovation / evidence are about and how this can help patients. This does not act as a substitute for face to face meetings and networking

Plain English summaries of research should be available

Settings

Publicity for new innovations and research findings can be targeted at and adapted to various settings. These could include; Community Centres; Supermarkets; Gyms & Leisure Centres; Libraries; Bus Stops; Garages; Hairdressers; Social spaces more positive spaces than hospitals; Day care centres; retirement villages; care homes; University student unions; Staff groups; U3A or similar community education organisations; Parish noticeboards; public transport; support groups and local charity branches; Charity shops; WI groups; Rotary groups; Lions groups; Round Table groups.

Clinical settings could include; Primary Care Centres; hospital departments; hospital atriums; pain clinics; pharmacies; PPGs; physiotherapy clinics; occupational therapy clinics alternative therapy clinics e.g. acupuncture, chiropractor, osteopaths,

Keep in mind that lay language will vary to different social contexts e.g. a school vs a GP waiting room vs an exercise centre

Champions

Successful implementation and dissemination can be bought about by champions – whether this be patient champions or clinical champions. These people act as change agents whilst keeping the human side to the evidence, promoting the innovation / evidence and maintaining a level of enthusiasm and drive.

A team of clinical and patient champions can work together as part of the innovation package and not just be used to simply roll it out.

Clinical champions could include: Allied Health Professionals; GPs; Nurses; Pharmacists; Coordinators; GP Practice groups

Patient, public and community champions could include: Patients; Friends; Family; Carers; Coordinators; PR people; Famous and high profile people; Soaps, radio and TV dramas (Using storytelling and incorporating the innovation / evidence into character stories); Charity trustees; MPs; Mystery Shoppers

Patients can take on various champion roles, including; Patients as educators; Patients as lobbyists; Patients as community outreach partners; Patients to challenge clinicians; Patients as advocates; Patients as Ambassadors; The Link Group can provide a second opinion and fresh eyes to projects.

Patients are often able to ask the difficult questions that professionals cannot, they are also able to tell their own patient stories and explain to the professionals who may wish to take up the innovation why they should be using it, how they can use it and how it could make a difference to a person's care.

It is important that groups of champions work together and share innovations and findings. Groups of engaged and enthusiastic people can have a positive knock on effect from one group to another.

Remember the power of patient stories - Humanising the evidence, making it interesting and relatable to people

Networks

Target networks and work with groups to scale up and scale out the innovation / findings. Champions with links to wider networks can facilitate this.

Groups could include; Charities; University of the Third Age (U3A); Patient Participation Groups; using peer support groups; condition specific support groups (in person, online); National Patient Voice and National Patient networks; Academic Health Science Networks; Integrated Care Systems); Women's Institute (WI) groups; Rotary groups; Lions groups; Round Table groups

The Link Group have a list of networks which you may find helpful, included at the end of this document.

Events

Look for events to where you can take your innovation / findings

Target events such as; Roadshows; Patient Participation Groups and GP events; National condition specific awareness days; community events; foodbanks

DISSEMINATION IDEAS - AT A GLANCE

PLATFORMS	TRADITIONAL	DIGITAL	OTHER
	<p>Word of Mouth</p> <p>Posters</p> <p>Information Boards</p> <p>Magazines</p> <p>Newspapers</p> <p>Information leaflets</p> <p>Newsletters</p> <p>Bookmarks</p> <p>Letters</p> <p>Face to face meetings</p>	<p>Apps</p> <p>Vlogs</p> <p>Blogs</p> <p>Videos</p> <p>Podcasts</p> <p>Social Media</p> <p>Youtube</p> <p>Infographics</p> <p>Visual information / illustration</p> <p>Email newsletters</p> <p>Apps</p> <p>Websites</p> <p>NHS</p>	<p>Presentations</p> <p>Journals</p> <p>Publications</p> <p>Adverts</p> <p>GP TV screens</p> <p>Radio</p> <p>TV</p> <p>Patient information stands</p> <p>Billboards</p> <p>Professional conferences</p> <p>National awareness days</p>
SETTINGS	KEELE	CLINICAL	COMMUNITY
	<p>Staff forums</p> <p>Student union</p> <p>Health education programmes</p>	<p>Primary Care Centres</p> <p>Hospital departments / atriums</p> <p>Pain clinics</p> <p>Pharmacies</p> <p>Patient Participation Groups at GP practices</p> <p>Physiotherapy clinics</p> <p>Occupational therapy clinics</p> <p>Alternative therapy clinics (e.g. acupuncture, chiropractor, osteopath)</p> <p>GP practices</p> <p>Support groups</p> <p>Local health charity branches</p>	<p>Community Centres</p> <p>Supermarkets</p> <p>Gyms & Leisure Centres</p> <p>Libraries</p> <p>Bus stops / public transport</p> <p>Garages</p> <p>Hairdressers</p> <p>Social spaces</p> <p>Day care centres</p> <p>Retirement villages</p> <p>Care homes</p> <p>University of the Third Age (U3A)</p> <p>Parish noticeboards</p> <p>Charity shops</p> <p>Women's Institute</p> <p>Rotary groups</p> <p>Lions groups</p> <p>Round Table groups</p> <p>Foodbanks</p>

CHAMPIONS	KEELE	CLINICAL	COMMUNITY
	<p>Link Group RUG group Patient champions Staff Students Coordinators</p>	<p>GPs Nurses Pharmacists Allied Health Professionals Practice Managers Clinical Commissioning Groups Coordinators Practice Managers Patient Participation Groups</p>	<p>Friends Family Carers Community groups Famous / high profile people Soaps, radio and TV drama actors Charity board members / trustees MPs Clinical mystery shoppers</p>
NETWORKS	KEELE	CLINICAL / RESEARCH	COMMUNITY / CHARITY
	<p>Link Group Link Group networks RUG group Staff Students Impact Accelerator Unit International implementation project partners</p>	<p>GP network Nurse network Pharmacy network Allied Health Professionals network Patient Participation Groups Clinical champions Public Involvement and Lay Accountability in Research and Innovation (PILAR) West Midlands Knowledge Mobilisation Collaboration ARCs Academic Health Science Networks Integrated Care Systems</p>	<p>Public Relation consultants Journalists Marketing departments High profile community members, e.g. MPs Charities and Community groups PIER (Patient Information Education and Resource Centre), Haywood Hospital Versus Arthritis Arthritis and Musculoskeletal Alliance (ARMA) The Haywood Foundation University Hospitals North Midlands Charity Women's Institute (WI) Rotary Groups Lions Groups Round Table Groups</p>

EVENTS	KEELE	LOCAL	NATIONAL
	Link Group meetings RUG annual event Best Practice Day Student Symposium	GP open days Patient information days Roadshows Foodbanks Local debates and forums	Charity awareness days Professional conferences National debates and forums National and international condition specific awareness days

Students

Students are also encouraged to think about and plan dissemination and promotion of their research findings. It's important to remember:

- Be aware of the limited time and means for students to innovate/disseminate
- It's important for students to consider feasibility and understanding (projects will be a learning curve and therefore more time may be dedicated to developing skills than innovation/dissemination)
- Much more restricted in scope of projects - likely to be local and have less impact

Students can consider Knowledge Mobilisation and dissemination activities through Postgraduate Conferences and Symposiums, internal seminars, theme meetings, Keele ASPIRE conference (medical), students Talking About Research, collaboration with supervisors. Students can include consent to contact participants to provide study findings/outcomes in their ethics applications, engage with other departments outside of their own, take part in a university Three Minute Thesis competition, Postgraduate coffee mornings or include their findings in medical / physio / psychological undergraduate teaching. Other ideas include reporting/presenting to funders, presenting at conferences (particularly for early career researchers), creating E-posters for conferences (often no need to attend), writing for 'The Conversation', writing commentaries for journals, collaborating with other universities, feeding back to places of recruitment, writing journal articles, disseminating to relevant local professionals, through their place of work (especially for students who also work clinically) and through supervisors' networks, collaborations and presentations.



TOP TIPS

*For implementation
& knowledge mobilisation
activities from patients and
the public*



- 1 Think about implementation AT THE START of research
- 2 Create ways to 'market' your research to the public
- 3 Have a clear implementation route and consider impact
- 4 Look at embedding your knowledge into education
- 5 Remember the power of working together with volunteers and champions
- 6 Address potential barriers early on
- 7 Recognise quick wins
- 8 Information needs to be clear, engaging and positive
- 9 Plan ahead to evaluate the innovation
- 10 Share outcomes in a meaningful way to all stakeholders



- 1) Think about dissemination and implementation strategies AT THE START of your research project
- 2) Create ways to market your research to the public. Consider the evidence based resource as a product and 'sell' and promote it as such. A change in mind-set is needed, shifting away from research to marketing, promotion and education. The ultimate goal is for the evidence to become general knowledge.
- 3) Have a clear implementation route and consider impact. Have identifiable pathways for all concerned to enable PPIE to contribute effectively. Start local to the project and move on to national / start traditional and move on to new. Consider phased dissemination and implementation. Establish regionally clearer structures between academic research outcomes and PPIE groups. Establish some implementation collaboration/network between all PPIE groupings including PPGs and ICSs to enable them to be better informed and clarify their contributions. A patient who has been involved in the project could take the evidence out to regional level nurses / GP champions in a group of pilot practices to then show the way forward. Phased roll outs can follow patient pathways, for example GP surgeries, followed by hospitals, followed by pharmacies, followed by other clinical treatment areas (e.g. physio) followed by community.
- 4) Look at embedding your knowledge into education. Think about embedding PPIE into medical / nursing schools; Lessons in U3A; Educating young people early on – projects in schools; University or college student noticeboards
- 5) Remember the power of working together with volunteers and champions. Spread research into practice supported by the Link Group and IAU. Remember the power of the patient voice – a patient project champion can link with nurse / doctor practice teams and project teams. Consider training patient experts. Patient led practical information and advisory groups can get results / findings to participants and wider public. Link with PPIE groups for General Practices. More patient led services improving primary care will positively impact on secondary care. Think of your team as The A Team – a team of local champions made up of GPs, physios, nurses, patients working and meeting together as one team. Find volunteers in specific geographical and clinical areas. Target existing volunteer groups to disseminate.
- 6) Address potential barriers early on. These can include - Cultural opposition; Reluctance to change; The complexities of large organisations like the NHS; Differing local and regional groupings and networks; There is no 'one size fits all' way to communicate, so use a variety of different ways; Not losing the 'human side' or the patient story / the patient voice; Cost / funding; Repetition
- 7) Recognise quick wins. Who's engaged with your project from the start? Don't overlook the obvious.
- 8) Information needs to be clear, accessible, engaging and positive. Patient information needs to be easy to share, accessible and language needs to be right, not just lay but also persuasive, engaging and positive
- 9) Plan ahead to evaluate the innovation. Evaluate whether the innovations have made a difference. Measure effects by looking at engagement with the resource, e.g. web hits, number of products needed, social media, number of times contact has been made with the charity, audit etc. Think about having an evaluation team to collect feedback and to research where patients who are using the innovation / findings have heard about them.
- 10) Share outcomes in a meaningful way to all stakeholders. Make sure you recognise what is important to each stakeholder and tailor your strategy to different contexts and stakeholder priorities, i.e. what are the key messages for public members, GPs, commissioners etc. Often quick, visual information is effective, e.g. infographics. Mobilising the knowledge means investing in two way relationships, building trust and adapting innovations to people's contexts.

TOP TIPS

For including patients and the public in implementation and knowledge mobilisation activities

1

Develop PPIE in implementation relationships early on in research



2

Find people with links outside of healthcare



3

Remember it is a two-way exchange of knowledge



4

Co-production is a journey of discovery



5

Keep in simple!



ACKNOWLEDGEMENTS

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With thanks to Dr Sue. Ashby, Keele University Research User Group, Versus Arthritis, the Impact Accelerator Unit, the PPIE team, Hollie Birkenshaw (for support with the student specific information) for their contributions.

KD is part-funded by a Knowledge Mobilisation Research Fellowship (KMRF-2014-03-002) from the NIHR and the NIHR Collaborations for Leadership in Applied Health Research and Care West Midlands. The views expressed in this paper are those of the author(s) and not necessarily those of the NHS, the NIHR, or the Department of Health and Social Care.

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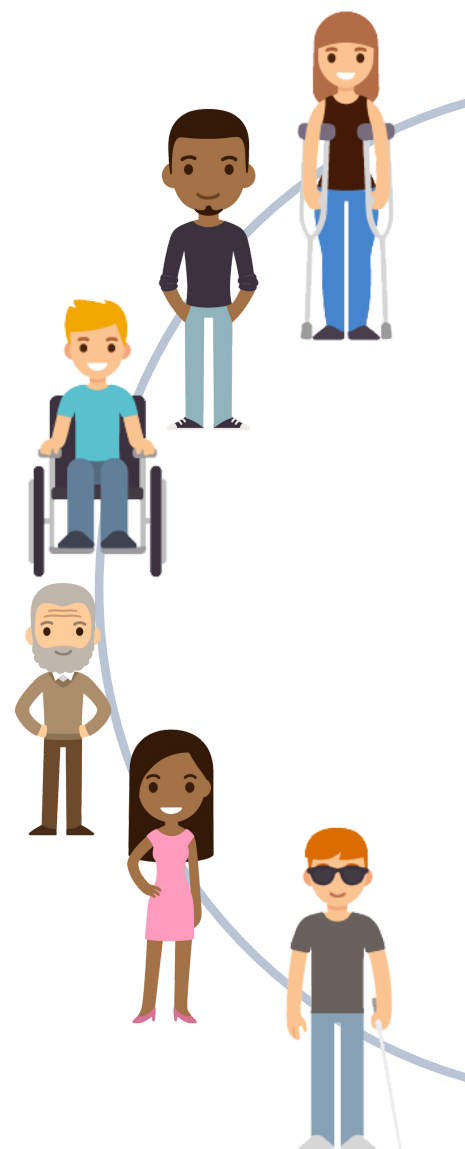
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