



James Lind Alliance

Tackling treatment uncertainties together (Patients and Clinicians)

- The Why
- The What
- The How
- The Questions
- The Future



James Lind Alliance

- Tackling Treatment Uncertainties Together
- The Why





The How

The five stages of a PSP



Going the extra mile...

Reaching out to survivors of stroke for their research questions

Alex Pollock on behalf of the JLA Life after Stroke PSP

nmahp-ru
Nursing, Midwifery and Allied Health Professions Research Unit

Improving health through research  CHIEF SCIENTIST OFFICE

DORIS 
database of research in stroke



Research priorities relating to life after stroke

1. Establish scope of PSP

2. Gather treatment uncertainties

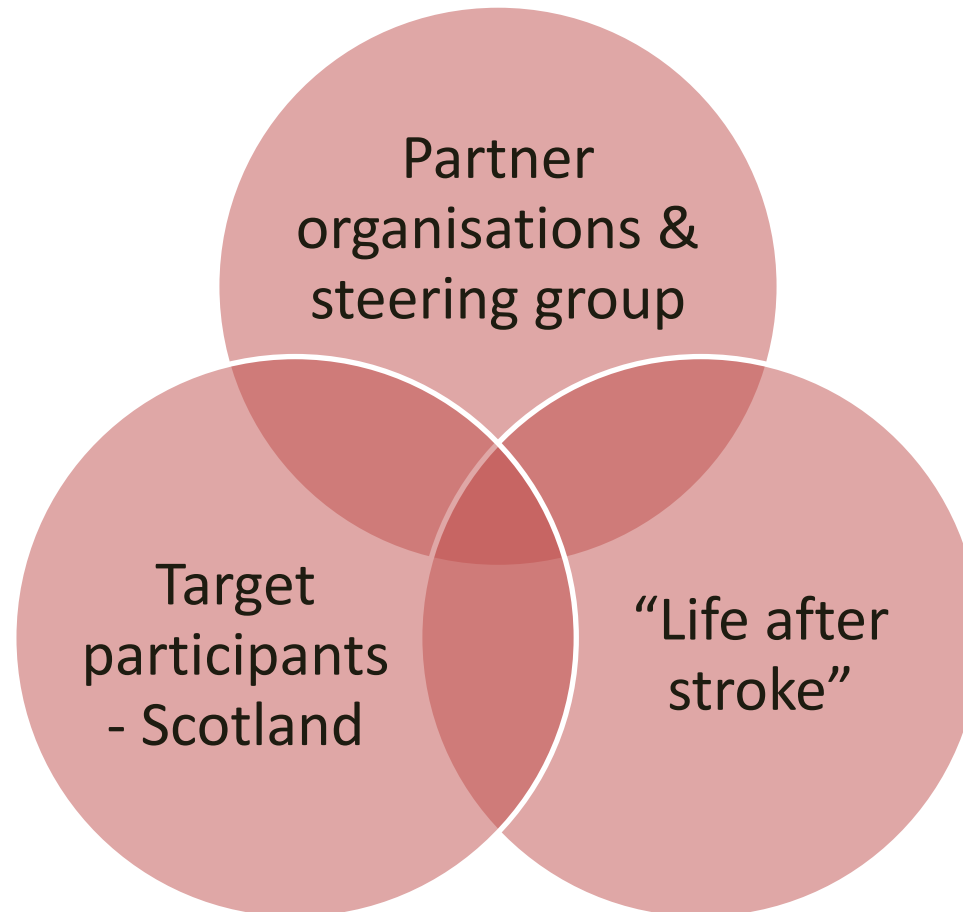
3. Check treatment uncertainties

4. Interim prioritisation

5. Final priority setting

Research priorities relating to life after stroke

1. Establish scope of PSP



Research priorities relating to life after stroke



2. Gather treatment uncertainties

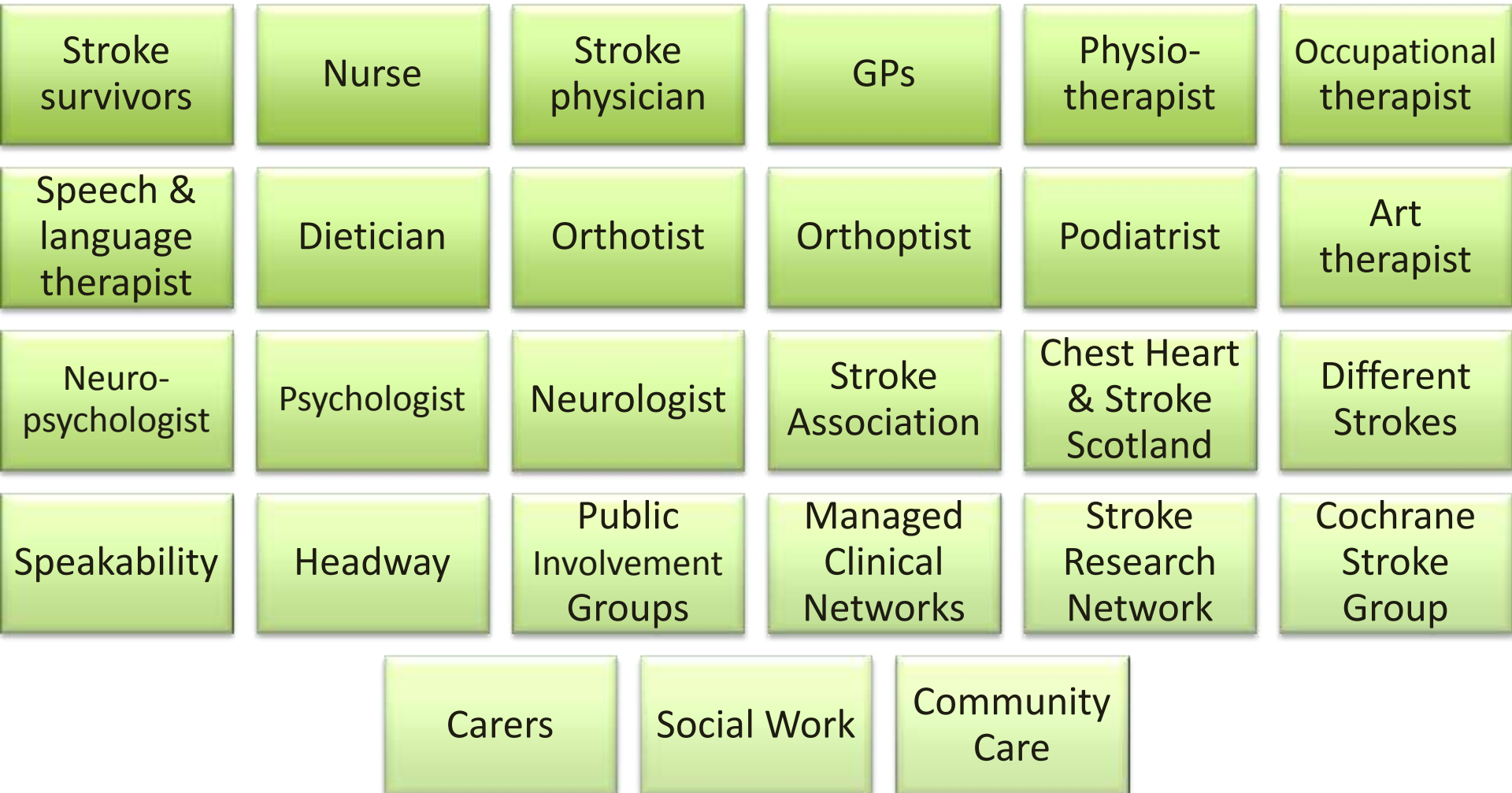
Methods

Emailing & posting

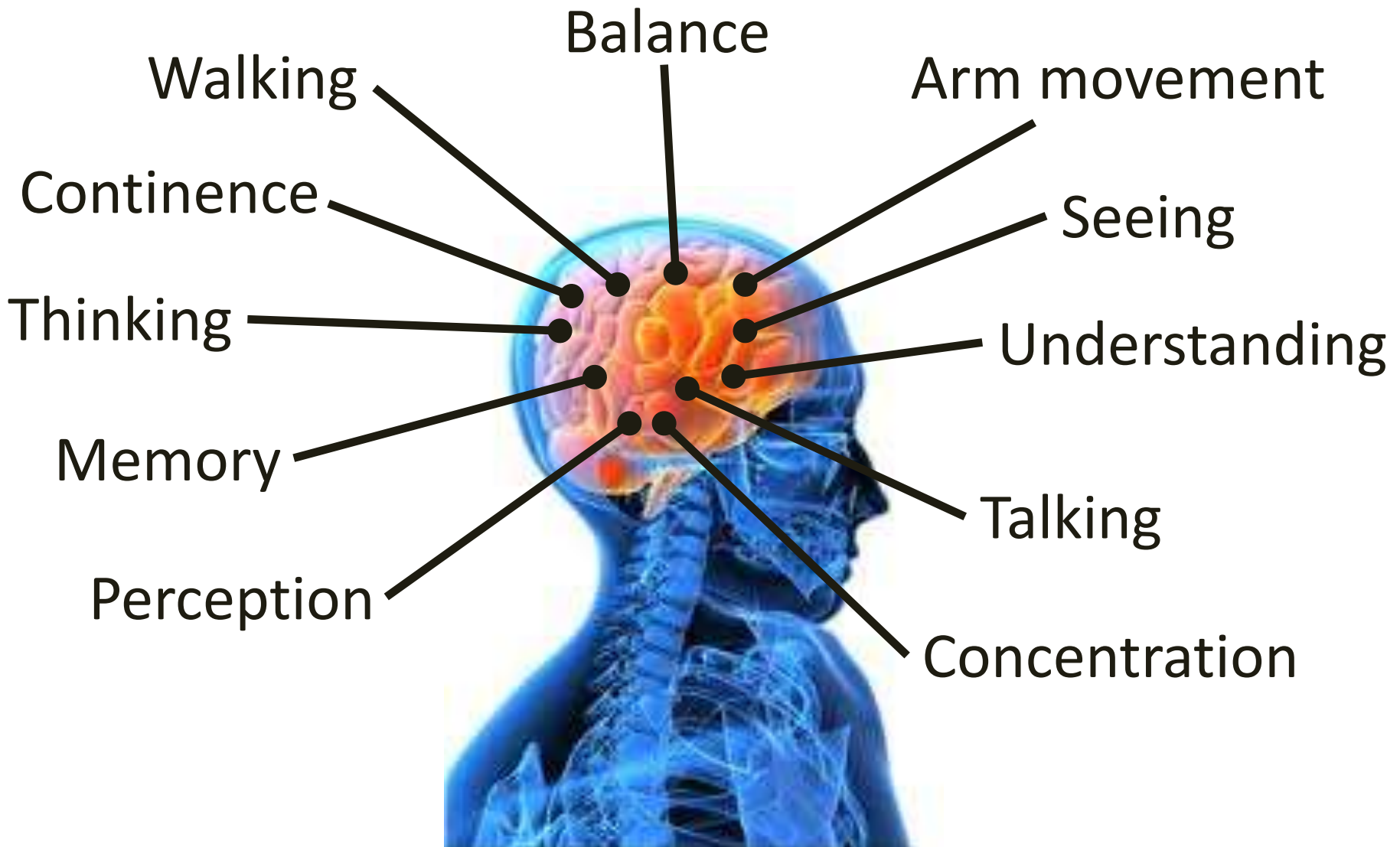
National meetings

Searching literature

Research priorities relating to life after stroke



Barriers to Involvement

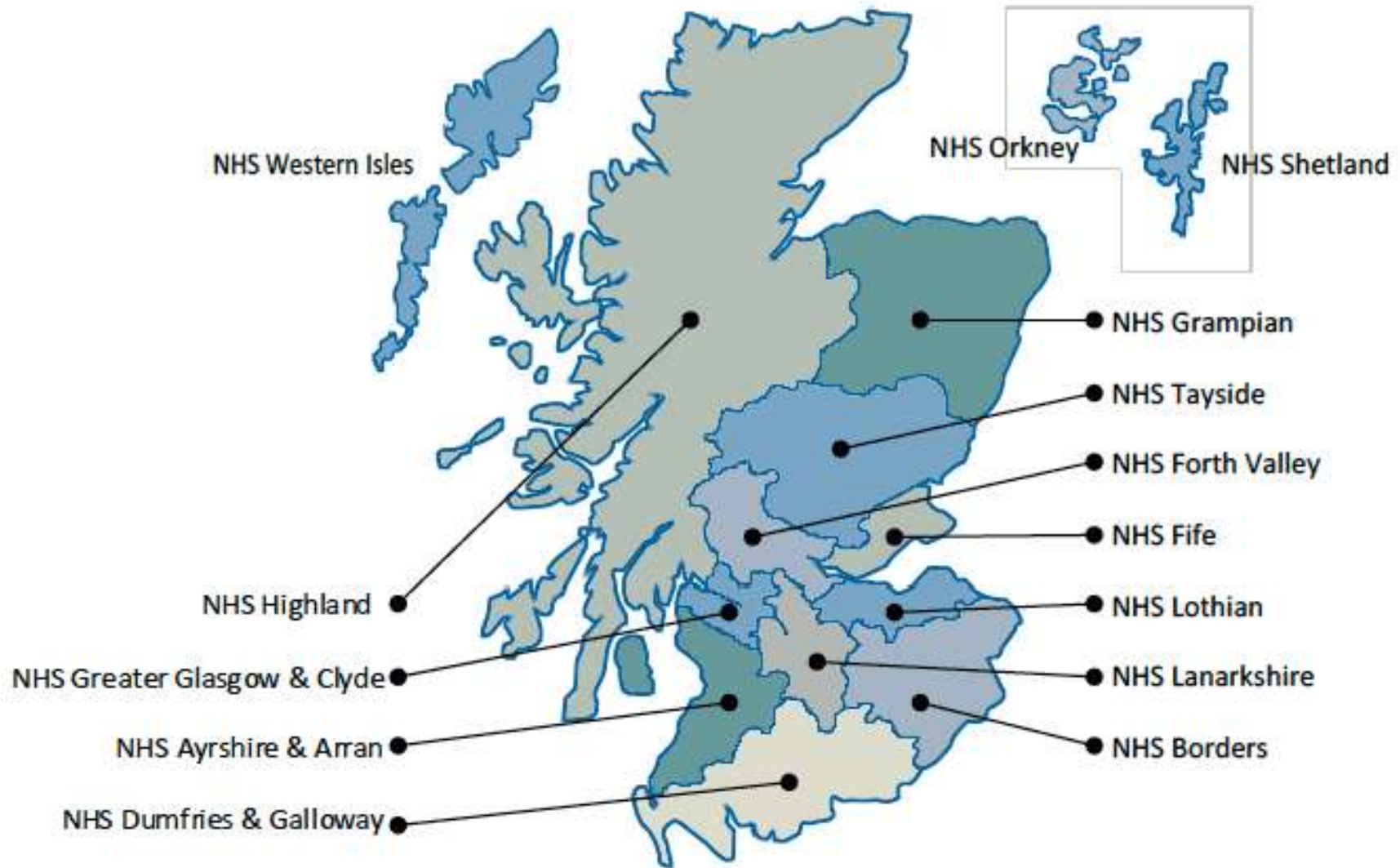


Barriers to Involvement

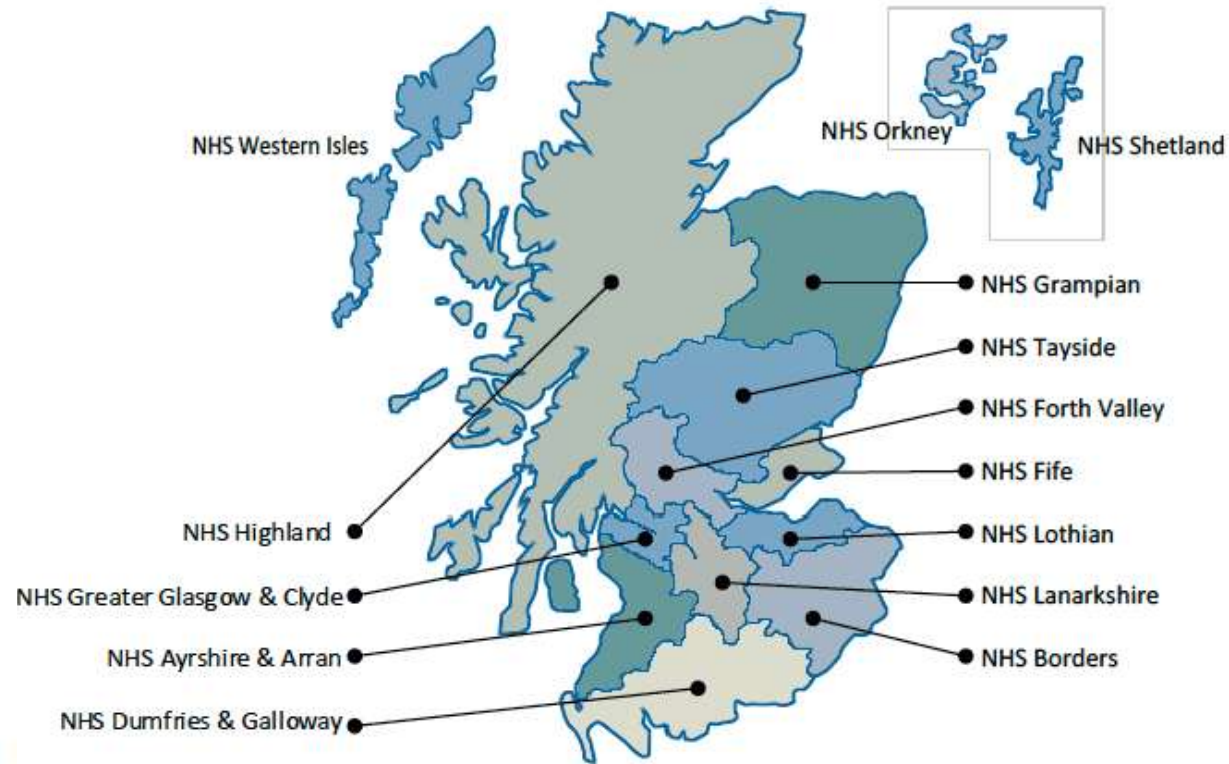
SCOTLAND



Barriers to Involvement



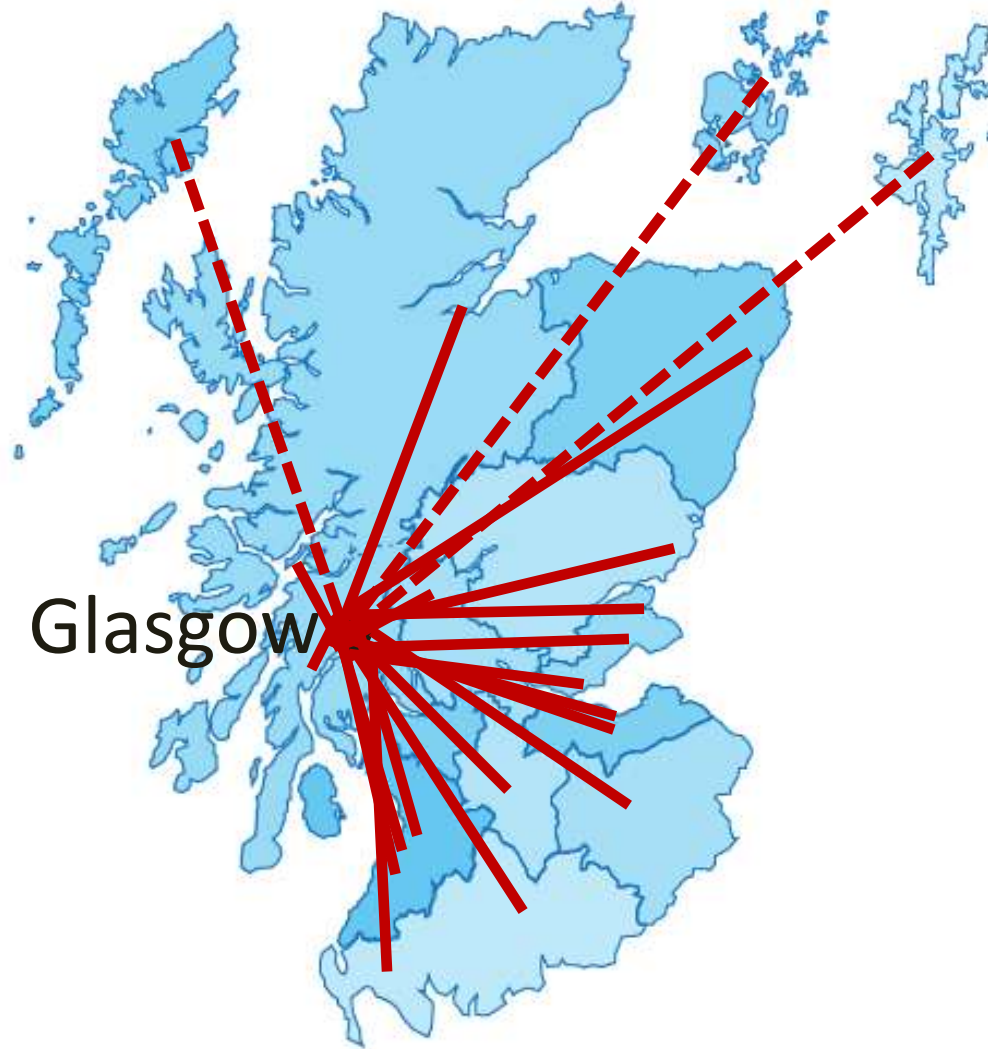
Going the extra mile



Going the extra mile



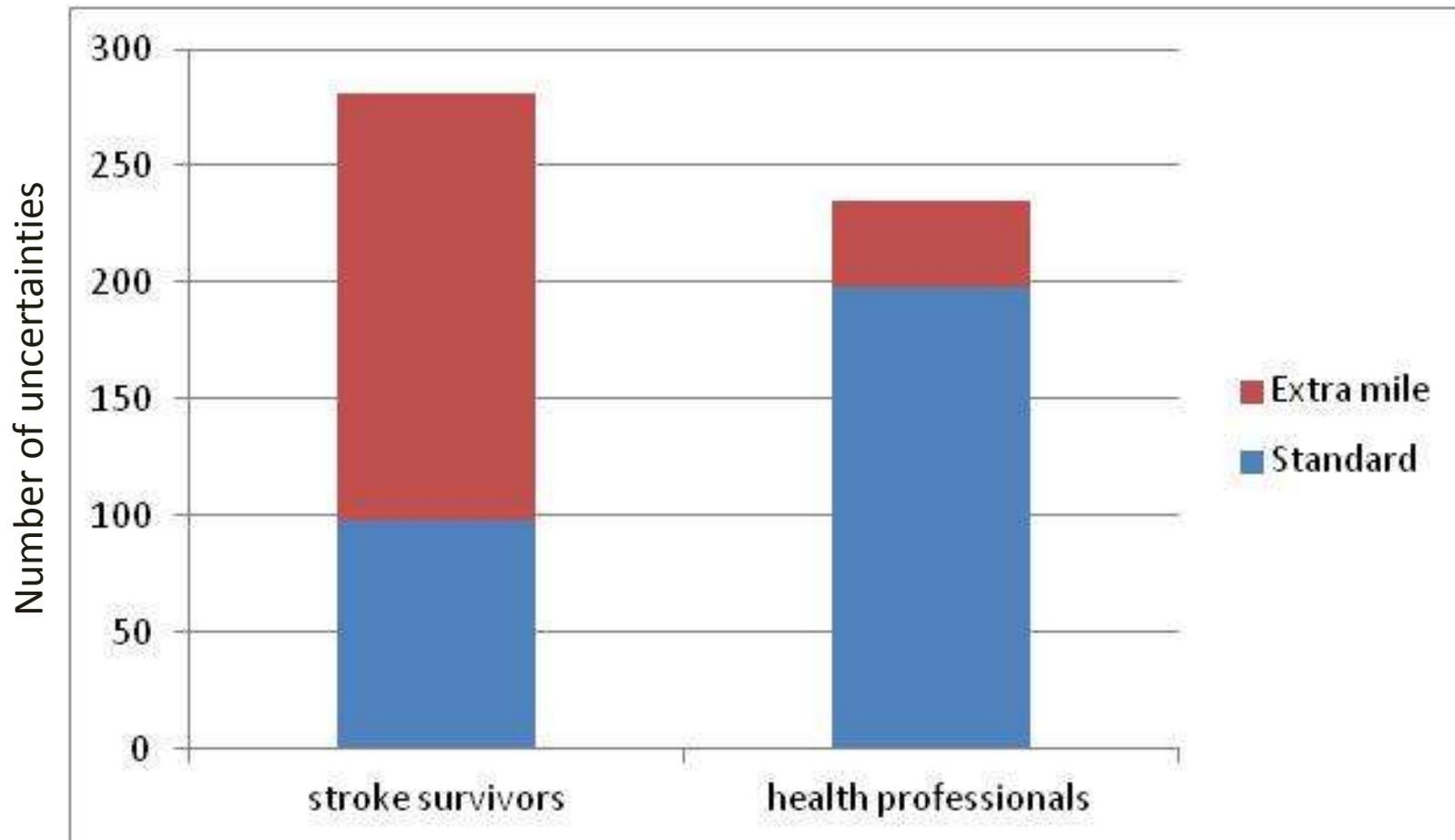
Going the extra mile



**Extra
1000
miles!**

Were the extra miles worth it?

Submitted treatment uncertainties



Research priorities relating to life after stroke

1. Establish scope of PSP

2. Gather treatment uncertainties

3. Check treatment uncertainties

4. Interim prioritisation

5. Final priority setting

Top 10 life after stroke research priorities

1. What are the best ways to improve **cognition** after stroke?
2. What are the best ways of helping people come to terms with the **long term consequences** of stroke?
3. What are the best ways to help people recover from **aphasia**?
4. What are the best treatments for **arm recovery** and function?
5. What are the best ways to treat **visual problems** after stroke?
6. What are the best ways to manage and/or prevent **fatigue**?
7. What are the best treatments to improve **balance, gait and mobility**?
8. How can stroke survivors and families be helped to cope with **speech problems**?
9. What are the best ways to improve **confidence** after stroke, including stroke clubs/groups, offering support, one-to-one input and re-skilling?
10. Are **exercise classes and fitness programmes** beneficial at improving function and quality of life and avoiding subsequent stroke?

Conclusion: were the extra miles worth it?





Alex Pollock
NMAHP Research Unit
Glasgow Caledonian University
Cowcaddens Road,
Glasgow G4 0BA
Scotland, UK

alex.pollock@gcu.ac.uk



Pressure Ulcers @JLAPUP

1h

Using social media for gathering and prioritising research questions from patients, carers and health professionals **#toomanytweets?**

Expand

Richard Morley – James Lind Alliance Pressure Ulcer Partnership





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What is social media? **#confused**
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1h





Pressure Ulcers @JLAPUP

1h

We created a website <http://t.co/A2ZIBxT6> and linked to online gathering and prioritisation questionnaires @SurveyMonkey

Expand

THE UNDER FIFTY
WOUNDS ONE IN THE UK
EIGHTH IN THE WORLD

- James Lind Alliance Pressure Ulcer Partnership
- The Survey
- About Us
- Our Plan
- Our Members
- Get involved
- Useful links
- Wounds research for patient benefit programme
- Advice on Pressure Ulcers
- Members Area

James Lind Alliance Pressure Ulcer Partnership (JLAPUP)

What do we need to know in order to improve prevention and treatment of pressure ulcers (bed sores)?

What are the questions about pressure ulcer prevention and treatment that matter most to patients, carers and clinicians?

We think it is vital that any further research into the prevention and treatment of pressure ulcers should focus on questions that are important to people with, or at risk of pressure ulcers, the people who care for them and the health professionals (doctors and nurses) who treat and help prevent these ulcers.

Please help by taking part in our new [survey](#).

Between January and May 2012 we asked patients, carers and health care professionals where they would like to see further research or where they thought there was uncertainty about the best medical and nursing care. We gathered nearly 1,000 questions about pressure ulcer prevention and treatment. A quarter of these were non-intervention questions (for example the biology of pressure ulcers, how they are distributed through the population, environmental factors and so on) and we will report on these questions separately. Three quarters were about what works in pressure ulcers treatment and prevention. We have now sorted and categorised these questions and checked to see where existing research already provides a reliable and complete answer. All intervention questions without a reliable or complete answer and where further research is called for, are being published on NHS Evidence in the UK Database of Uncertainties about the Effects of Treatments (DUETs) <http://www.library.nhs.uk/duets/>

Now, from the most frequently asked questions, for which we do not have reliable answers, we want your help to identify the most important questions for future research.

We do not have evidence-based answers for the questions in the survey and we do not expect you to have answers for them. For example, with regard to the question on turning frequencies, we aren't asking how often people think patients should be turned. What we want to know is how important it is to you that research



Pressure Ulcers @JLAPUP

We created a Facebook account #not_very_much_visited

1h

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Leeds Community Healthcare

Wounds research
for patient benefit

THE UNIVERSITY of York



Pressure Ulcers @JLAPUP

1h

We created a Twitter account, tweeted >230 times, follow 138, have 110 followers #pressureulcers #calltoaction

Expand

Pressure Ulcers (JLAPUP) on Twitter - Mozilla Firefox

Wounds UK takes James Lind Alliance... James Lind Alliance Pressure Ulcer Pa... Pressure Ulcers (@JLAPUP) on Twitter

Twitter, Inc. (US) | https://twitter.com/JLAPUP

Home @ Connect # Discover Me Search

Pressure Ulcers @JLAPUP

The James Lind Alliance Pressure Ulcer Partnership. Identifying research priorities for the prevention and treatment of pressure ulcers.

York <http://www.japressureulcerpartnership.co.uk/>

Edit your profile

231 TWEETS

138 FOLLOWING

110 FOLLOWERS

Tweets

Following

Followers

Favorites

Lists

Recent images

Similar to you

WOUNDS Journal @WOUNDSJournal

Eykona @Eykona

https://twitter.com/following

Pressure Ulcers @JLAPUP 4h
@TMJ_LHCW @NHSMidlandsEast Dear Champions, please champion our #pressureulcer survey! tiny.cc/15nuw
View conversation

Pressure Ulcers @JLAPUP 21h
Little evidence of effectiveness of #pressureulcer interventions in form of fair trials. How do we know what works? tiny.cc/15nuw
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Pressure Ulcers @JLAPUP 8 Oct
79 people have already taken part in our #pressureulcer survey tiny.cc/15nuw Your chance to influence future research!
Expand

Pressure Ulcers @JLAPUP 8 Oct
@NHSManchester @NHSMidlandsEast interested in PUs? Take this survey and help influence future research tiny.cc/15nuw
View conversation

1324 06/10/2012



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1h

We joined You Tube to explain how to complete the prioritisation survey, embedded it in the survey.

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Mary Madden's blog "Are medical conferences useful?"

<http://tiny.cc/a3pylw>

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Mary Madden: Are medical conferences useful?
25 Apr, 12 | by BMJ Group



In his recent Viewpoint piece [1], John Ioannidis asks whether medical conferences serve any useful purpose other than as carbon-guzzling showcases for opinion leaders and pharma-funded research. He also proposes that nobody with ties to industry over the last 3 years be allowed to organise a conference. Ioannidis' concerns resonate loudly following my participant observation at a UK wound care conference [2]. There are no industry-free scientific conferences in a sector where medical device companies develop close relationships with clinicians through sponsorship of conferences and continuing professional development education and training.

Clinicians respond, and need to see themselves responding to facts, figures, and studies. At the same time, marketers see these as a means of increasing sales. "Conference" is perhaps a misnomer for the event I attended which was in effect a trade fair featuring sponsored champagne receptions, a conference gala dinner, and a large confectionary-filled exhibition promoting existing and new technologies in wound care prevention, diagnostics, and treatment. Scientific scrutiny and scepticism were notably absent in sponsored plenary sessions which sought to present particular products in the best possible light, with clinician satisfaction standing as evidence of effectiveness.

Wound care management is big business in the UK with a turnover exceeding £1bn in 2009 [3]. Most wound care interventions are classified as devices rather than medicinal products. A light touch European regulatory focus (CE marking) [4] on safety assessment

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- Letters: Bring back the paper in the print BMJ (2012)
- Practice: Rhabdomyolysis co-prescription of statins (9 Oct 2012)
- Letters: Selective dorsal rhizotomy remains effective in cerebral palsy (9 Oct 2012)
- Letters: Early radiographic surveillance is needed to prevent sequelae of hip displacement in cerebral palsy (9 Oct 2012)

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- Reducing emergency admissions: are we on track? (28 Sep 2012)
- Newer insulins and...

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Wounds research
for patient benefit



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What doesn't work **#toptips**
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#Facebook
#Twitter-hacked
#traditional_methods_still_needed
#time-consuming
#distracting

The James Lind Alliance
"Tackling treatment uncertainties together"



Leeds Community Healthcare

Wounds research
for patient benefit

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What works #toptips

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#Twitter

#You Tube #people_don't_read

#regular_tweets

#call_to_action #surveys

#fun!

@direct_messaging

#increasingly_provocative

#RT

#344 online participants in "Gathering" survey

#88 participants in "Prioritisation" survey to date

#younger-people

#silver surfers





Pressure Ulcers @JLAPUP
@NIHR #Disclaimer
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1h

This study presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research funding scheme (RP-PG-0407-10428). The views expressed in this presentation are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health



Eczema PSP – Turning an uncertainty into a research question?

Amanda Roberts and Tessa Clarke
on behalf of the Eczema PSP Steering Group

NOTTINGHAM SUPPORT GROUP FOR
CARERS OF CHILDREN WITH ECZEMA



Aim of the PSP

- A collaborative project - Partnership between patients, carers, health professionals and researchers.
- Continue this through to developing research questions.



Top 14 not Top 10

Shared priorities

- What is the best and safest way of using topical steroids for eczema: frequency of application, potency, length of time, alternating with other topical treatments, and age limits for treatment?
- What is the long term safety of applying steroids to the skin for eczema?
- What role might food allergy tests play in treating eczema?
- Which emollient is the most effective and safe in treating eczema?

Patient and carer priorities

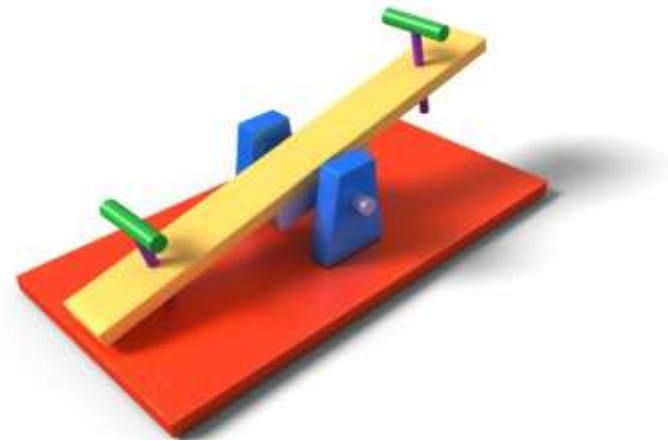
- What is the best psychological treatment for itching/scratching in eczema ?
- Which is the best way for people with eczema to wash: frequency of washing, water temperature, bath versus shower ?
- What are the best and safest natural products to apply to the skin for eczema?
- How much does avoidance of irritants and allergens help people with eczema ?
- What is the role of diet in treating eczema: exclusion diets and nutritional supplements ?

Health professional priorities

- Which is more effective in the management of eczema: education programmes, GP care, nurse-led care, dermatologist-led care or multi disciplinary care?
- Which is safer and more effective for treating eczema; steroids or calcineurin inhibitors?
- How effective are interventions to reduce skin infections in the management of eczema?
- Which should be applied first when treating eczema, emollients or topical steroids?
- What is the best and safest way of using drugs that suppress the immune system when treating eczema?

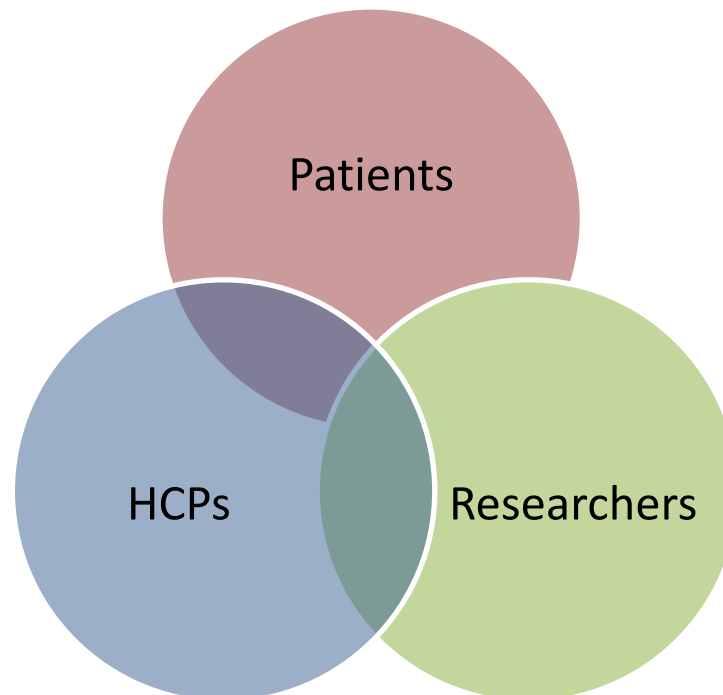
Balancing the top 14

- Some questions prioritised by one particular group were merged into 1 question,
- Some of these questions ranked highest by the health professionals ranked low on the combined list of priorities.
- Tried to allow a broader range of topics to go to the workshop stage whilst ensuring that each topic was appropriately considered.



Workshop for research questions

- Aim of the workshop - develop the top ranked uncertainties in to research questions.
- Real questions and indicative questions.
- Ensuring that patients were able to contribute fully in the process



The Patient Experience

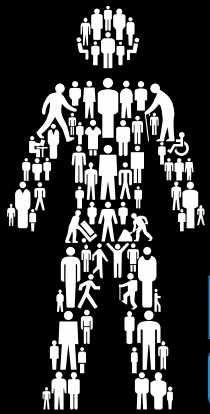
- Patients role in the workshop – able to provide real context to the questions.
- Uncertainty – a difficult concept:
 - Tendency not to question medical treatment.
 - We don't know what we don't know.
 - Patients are conditioned to live with a certain amount of uncertainty.

Summary

- **Lessons learnt -**
 - Lots of research questions from each standard question
 - Not all groups were able to move beyond their first shared priority
- **Successful collaboration** - Quality of decisions and research questions was high and could be endorsed by both patients, carers and clinicians.
- **More work to do.....**



The Final Stretch



**PROSTATE
CANCER UK**



But how do we get this funded?

Uncertainty

How can over-treatment for prostate cancer be prevented by identifying and excluding the treatment of harmless tumours?

Is there a genetic marker for prostate cancer that would be both more sensitive and more specific than PSA serum level?

What can be done to delay or prevent the onset of hormone independent prostate cancer?

Are there any dietary measures that can prevent prostate cancer or slow its progression?

Does serial PSA measurement in patients with prostate cancer accurately monitor disease progression?

Would prostate cancer screening targeted at high risk groups, i.e. those with positive family history, and ethnic minorities with higher rates, improve the outcomes of treatment in these groups?

Uncertainty cont.

Does active surveillance work for treatment of prostate cancer?

Do variations in GP awareness of prostate cancer affect outcomes?

What is the effectiveness of new treatments for prostate cancer such as High Intensity Focused Ultrasound and Cryotherapy?

Is there a vaccine that can prevent prostate cancer?

Are there any non-intrusive diagnostic tests that will identify aggressive prostate cancer patients whilst not identifying harmless cancers?

Collaboration is key

MRC

Other funders

Reporting back

Go through the process again?

Speak to patients and clinicians



What next?

