Agenda Item 3

STRATEGY …

… for the Patient and Public Involvement (PPI) Steering Group of the National Institute of Health Research (NIHR) Health Protection Research Unit (HPRU) in Chemical and Radiation Threats and Hazards, a major 5 year research project to investigate the effect on health of exposure to certain chemicals or radiation.

Brief description of the project

“The HPRU is one 13 funded by NIHR and will focus on conditions of medical concern where exposure to chemicals or to radiation may cause major health problems.
As examples, we shall investigate

Theme 1 (Radiation) if newer uses of X-ray machines might have adverse effects on health,

Theme 2 (Dermal) determine how UV light (from sunlight) could cause changes in the skin and increased sensitivity to chemicals.

Theme 3 (Liver) We shall also look at why some people develop the chronic liver disease primary biliary cirrhosis, which clusters in certain geographical regions and affects up to 20,000 people, and by determining if chemical exposures cause this disorder, develop methods to investigate how chemicals might cause other chronic diseases.

Theme 4 (Neuro) We shall develop methods to identify emerging recreational drugs (“legal highs”), which are being used by increasing numbers of people, to identify those associated with serious toxicity.

To achieve this work we shall bring together a team of investigators who are well known for their research expertise in the health effects of chemicals and radiation and with the capability to investigate large groups of patients and the public. The breadth and depth of the team will
provide Public health England (PHE) and the Department of Health (DoH) with advice on how best to use new X-ray machines, what can be done to balance the health risk/benefits of UV light exposure, how chemical exposures may lead to chronic diseases, and the best ways to investigate novel health problems that may be caused by chemical or radiation exposures.

Newcastle University is also working with another HPRU at King’s College London on 2 strands (more detailed description from NIHR website at annex A.)

Theme 5 personal decontamination following accidents involving chemicals and radiation.

Theme 6 on the detection of chemical hazards in an emergency situation.

**Objectives of PPI for this project**

Helping to shape research - are the right issues being addressed in the right way?

Understanding patient and public concerns and advising on how to communicate these given the sensitive nature of the topics - it is particularly important to understand public ‘risk perception’ and how to convey findings without causing undue alarm.

Explaining the work and consulting patients and public and potential implementers of the results - who and what about?

How to communicate eg with seldom heard groups - who are they, why are they seldom heard and how to communicate.

Investigate novel methods to communicate with young people about novel psychoactive substances (legal highs).

Designing events eg to disseminate research and obtain feedback on work - major event in years 3/4

Outcomes - publicising results; flag up potential barriers to implementation (cultural, organisational)

Evaluate performance
How they can be met

Membership of the Steering Committee - includes the project director, project coordinator, Public Health England, Lay PPI reps with a good range of contacts, interests and skills; Theme leaders or senior researcher for each theme, University engagement coordinator.

The Steering Committee

- agrees strategy for PPI for the HPRU and for 2 Joint themes with KCL
- relates to the individual themes through the committee members eg agrees PPI plans for each theme and receives regular reports on implementation; assists with design of events
- agrees annual plans to implement PPI strategy
- organises training and away days for members
- comments on proposals and reports
- advises on communications strategies
- organises major consultations and events – agree timetable eg in relation to major event(s) in years 3-4.
- evaluates its performance

Communications

The committee will develop a communications plan in line with this strategy with advice from the University press office and themes’ existing channels

Channels include

- traditional media
- website
- social media eg Twitter; Facebook; YouTube

The website should include a Section for PPI; members pen pictures.

Events

- an away day in November 2015 with Voice North members (or Research Support Group) to explore matters of public interest at outset.
• A major event halfway and at end. Decide on format eg one event or several? Audience? - Professors report plus opportunity to meet researchers?
• smaller events eg for children and young people at GN Museum on a Saturday?
• small focus groups - for individual themes to organise or general approaches to seldom heard groups to tell them in the whole range and encourage them to take an interest in the themes relevant to them? Reports to be made to the Committee.
• going out to meet interested and seldom heard groups - identify which and how to approach.

**Partnerships**

Develop relationships with key partners eg Foundation Trusts, Clinical Commissioning Groups, patient groups

• agree which groups each theme should be keeping in touch with and which are for the SC. List current contacts and assign them to theme or SC. Eg Foundation Trusts; Clinical Commissioning Groups; Local Authorities; patient groups; interest groups; Voluntary and Community Sector; seldom heard groups;
• Contact those responsible for planning for management of Regional Emergencies.
• identify gaps

**Management and Governance – all on agenda for first meeting and will be attached when agreed.**

Terms of Reference

Role and expectations of members

Support for Lay members

Training for members

**Resources**

Budget £8000 pa

Measuring success
Evaluation plan - including monitoring information to be collected- to be discussed with Prof Thompson and developed for discussion and agreement. To include

- Collect baseline information
- lay members to keep notes of contributions;
- annual questionnaire to collect information from researchers and lay reps.

Relationship to External Advisory Group (EAG)

Establish arrangements for liaising with the EAG and how PPI findings will be incorporated and used by EAG to help shape the research. EAG want to know what public thinks is important by this independent route.

Chair of PPI Steering Committee to be a member of EAG. EAG to meet all lay reps at appropriate point

Formal documents to be annexed when agreed

- Membership
- terms of reference
- checklists for involvement of lay members
- appointment letters for lay members
- pen pictures of members

Annex A

KCL Themes (Extract from NIHR website)

Theme 5: Improving the operational effectiveness of skin decontamination in exposure to toxic chemicals

Following a major incident involving exposure to a hazardous substance, it is often necessary to ask people to undergo decontamination using showering facilities erected by the emergency services.

This theme is developing the evidence-base for what constitutes effective decontamination.
Work is proceeding in two strands. In the first, laboratory evaluation of existing and novel methods for decontamination in acute chemical emergencies is being conducted, led by Newcastle University (Wilkinson).

One study is generating quantitative data on dermal “pick up” from materials, including contaminated clothing, to simulate contact with contaminated surfaces and measure the rate and extent of absorption through the skin of these chemicals under these conditions. The chemicals being studied include surrogates for chemical warfare agents and radionuclides.

This work will identify the dose-effect relationships influencing chemical transfer and absorption and test the effectiveness of rapidly deployable decontamination techniques compared with standard protocols.

A second project is assessing the “delayed” absorption of chemicals. Quantitative data on the influence of different skin decontamination regimes (including novel approaches using sponges, ionotropic agents and rapidly deployable techniques such as wet wipes) and exposure times on “reservoir effects” will be generated using surrogates.

This will determine whether the effectiveness of decontamination is altered by asking people to subsequently put clothes back on and whether decontamination redistributes the skin surface contamination over a wider skin area, reducing the effective skin loading.

Complementary work by the PHE Behavioural Sciences team (Amlôt) is examining proposed decontamination strategies in human volunteer trials using simulants, including the transfer of contamination during disrobing, the efficacy of rapidly deployable dry and wet decontamination options and the occlusive effect of re-robing.

The effect of responder communication strategies on decontamination efficiency (speed and protocol compliance) and effectiveness (removal of simulant contaminants) is also being assessed.

**Theme 6: Biomarkers in detection and triage**

Following a major incident involving a hazardous agent, one of the first priorities is often working out exactly what substance we are dealing with.

Work in this theme is focused on the development of robust, rapid and reliable biomarkers that enable the identification of a chemical or
radiation exposure and contribute to decisions about the management of casualties.

Using the substantial analytical resources of Newcastle’s Medical Toxicology Centre (MTC), we are conducting three main projects:

- project one is ‘field testing’ the use of an existing MTC laboratory assay of the systemic effects of nerve agent exposure as a rapid screening technique for large numbers of individuals presenting at a hospital. The basic equipment required for this assay is routinely available in hospital laboratories
- project two will develop novel biomonitoring methods to detect the use of organophosphates and identify the specific chemical involved
- in project three, we will identify the challenges of and opportunities in incorporating biomonitoring capabilities into a Concept of Operation for medical first responders