How is Academia Successfully achieving a patient-centric approach to research & teaching

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The project is receiving support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115334, resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007-2013) and EFPIA companies.

Academia and EUPATI: Achieving Meaningful Patient Public Involvement in research and education

Patients & public have an increasing key role in all aspects of health-related research

- DENMARK: University of Copenhagen
- BELGIUM: EORTC – Brussels
- UK: Universities of Leeds, Manchester and York

Academic & Clinical Research

Biopeople/University of Copenhagen The Patients' Academy:

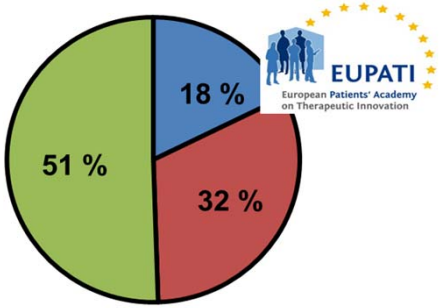
- Biopeople/University of Copenhagen's initial role in EUPATI was "***just***" course content development.

Biopeople/University of Copenhagen perspective on EUPATI and PPI

- A huge DK interest grew in EUPATI.
- A Danish ENP has been established and several local events focusing on “patient engagement” in medicines R&D had been organised.
- In January 2016 ten topics were translated into Danish and now the whole toolbox will be translated (originally no plans for ENP and Toolbox in Denmark).
- Biopeople was co-supervisor on a bachelor project; “Patients-positions and power” by Lotte Klim (Chairman of the Danish ENP)
- Biopeople got funding for ***Biomarkers as an emerging growth area***: The objective is to support the cross disciplinary biomarkers field and to **involve end users /patients** together with pharmaceutical R&D and information technology (ICT).

Key Danish activities

1) *Why patient involvement in medicines R&D to obtain better treatments (2014)*
2) *Patient involvement in medicines development and approval; Paradigm shift towards true patient impact in regulatory science (2015*) (***Proceedings published*** *in Therapeutic Innovation & Regulatory Science, 2016*)
3) *EUPATI TOOLBOX & Patient involvement in developing new medicines* (2016).
4) *Biomarkers as an* ***Emerging Growth area in Denmark*** *(2016) (whole session about patient/user perspective)* (***Pixie book published***)
5) *Biomarker AGORA* (***6 patient organisations had booths and exhibited activities linked to biomarkers***) http://www.bioagora.dk
6) In preparation: ***Patient involvement in medical research in Denmark*** (in collaboration with anthropologist and including participation of INVOLVE)



Distribution of participants; (blue) patient organisations, (green) academic and public institutions and (brown) private companies.
Altogether **191 participants** attended the first 3 events listed above

Future Danish activities

- Scandinavian collaboration expansion of Danish ENP in tripartite manner
- EUPATI DK plans for new collaboration with biobanks to educate about the use of biobanks in medicines R&D..
- January 2017 the Danish Medicines' Agency establish a new Medicines' Council that will include patients.
  - EUPATI DK has approached the agency to contribute patient education for patient members of the council & other aganecy committees

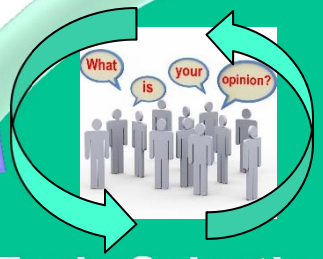

Two Danish EUPATI Fellows
BIO PEOPLE
Biomarkers as an emerging growth area
Biomarkers in Brief
EUPATI: Collaboration between patients, academia and industry to champion the informed patient in the research and development of medicines
Daphnee S. Pushparajah[1]*, Jan Geissler[2] and Niels Westergaard[3]
[1] UCB Pharma, Slough, UK
[2] European Patients' Academy on Therapeutic Innovation, Brussels, Belgium
[3] Biopeople, University of Copenhagen, Copenhagen, Denmark
DIA DEVELOP INNOVATE ADVANCE
Therapeutic Innovation & Regulatory Science
Commentary
A Paradigm Shift Towards Patient Involvement in Medicines Development and Regulatory Science: Workshop Proceedings and Commentary
Gitte Borup, MSc, Pharm[1,2], Karin Friis Bach, MSc, Pharm[1,2], Merete Schmiegelow, MSc, Pharm[4], Helle Wallach-Kildemoes, PhD[1,5], Ole Jannik Bjerrum, DMSc, MD[1,6], and Niels Westergaard, PhD, DSc, Pharm[1,3]

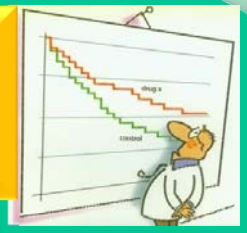
Academia and EUPATI: Achieving Meaningful Patient Public Involvement throughout the research cycle

Inclusive
Iterative
Robust
Methodology
e.g. James Lind Alliance

EUPATI
European Patients' Academy on Therapeutic Innovation

Delivering Patient Skills





Evidence –based Approach
e.g. user testing

1. Topic Selection/ Research Prioritisation

2. Design & Review

Academia and Patient Public INVOLVEMENT

4. Dissemination & Implementation

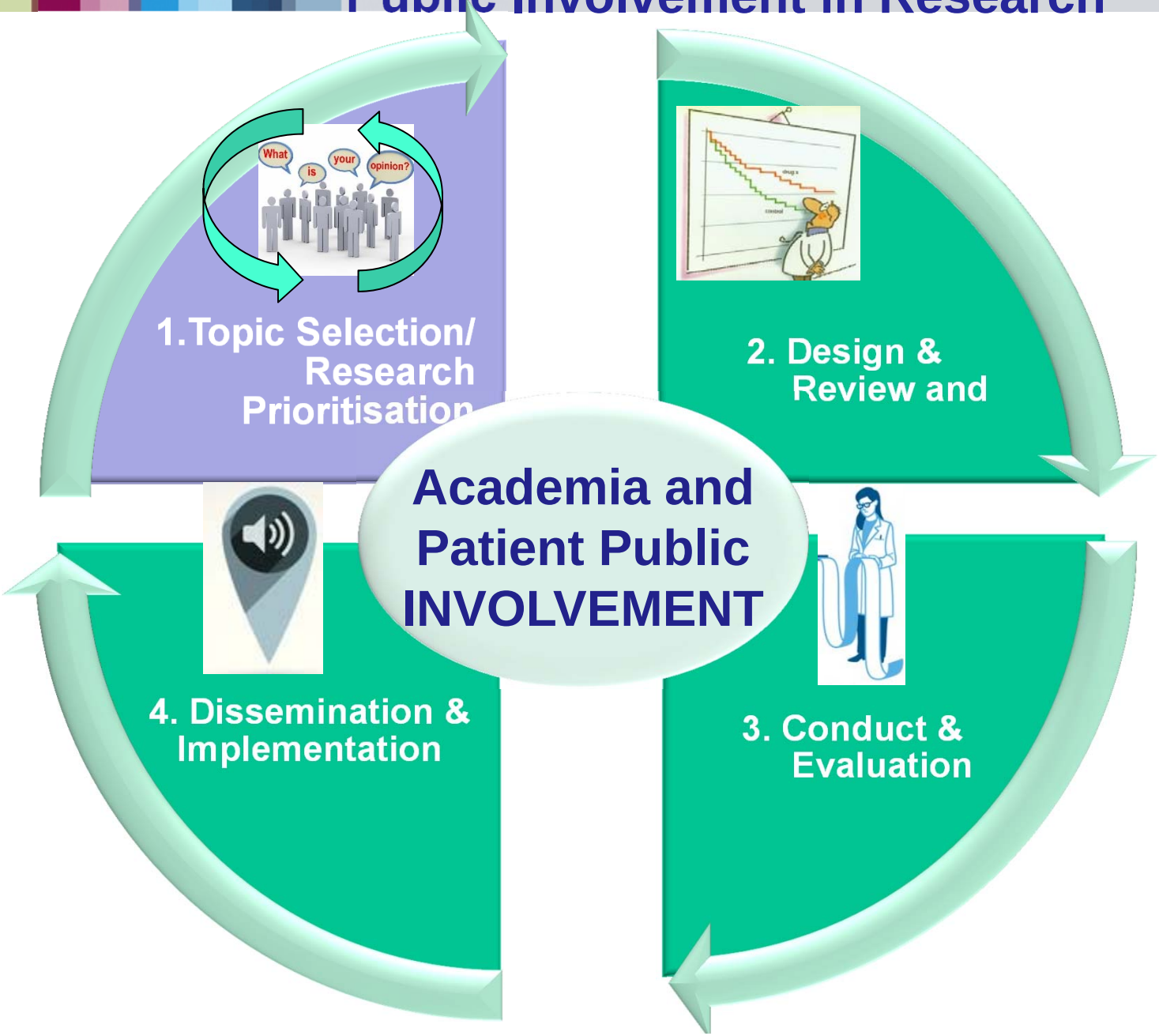
3. Conduct & Evaluation

Innovations to reach seldom heard

Academia Assessing Impact

Analytical & interpretative Innovation

Academia examples of Meaningful Patient Public Involvement in Research



1. Topic Selection/ Research Prioritisation

EUPATI Driving Academic Assessment of public involvement in medicines R&D

University of Manchester Drs Bella Starling & Suzanne Parsons

EUPATI
European Patients' Academy on Therapeutic Innovation
NEEDS ASSESSMENT

- Review of existing **information resources**; **230** resources reviewed.
- Review of **research literature**; **12600** titles and abstracts; **134** studies included
- **Public** survey; **6931** responses in GB, Spain, Poland, Italy, France and Germany
- **Patient advocate** survey; **468** responses across Europe
- **Patient advocate** survey focused on **course delivery**; 41 responses
- Qualitative research with **patients and the public**; **n=125** people
- Qualitative research with **stakeholders; n=56** (incl. policy makers, pharmaceutical industry, clinical research professionals)

Downloaded from http://bmjopen.bmj.com/ on April 18, 2015 - Published by group.bmj.com

Open Access Research

BMJ Open

What the public knows and wants to know about medicines research and development: a survey of the general public in six European countries

Suzanne Parsons,[1] Bella Starling,[1] Christine Mullan-Jensen,[2] Su-Gwan Tham,[3] Kay Warner,[4] Kim Wever,[5] on behalf of the Needs Assessment work package of the European Patients' Academy on Therapeutic Innovation (EUPATI) Project

To cite: Parsons S, Starling B, Mullan-Jensen C, et al. What the public knows and wants to know about medicines research and development: a survey of the general public in six European countries. BMJ Open 2015;5:e006420

ABSTRACT

Objectives: To explore public knowledge of, and interest in, learning more about medicines R&D in six European countries.

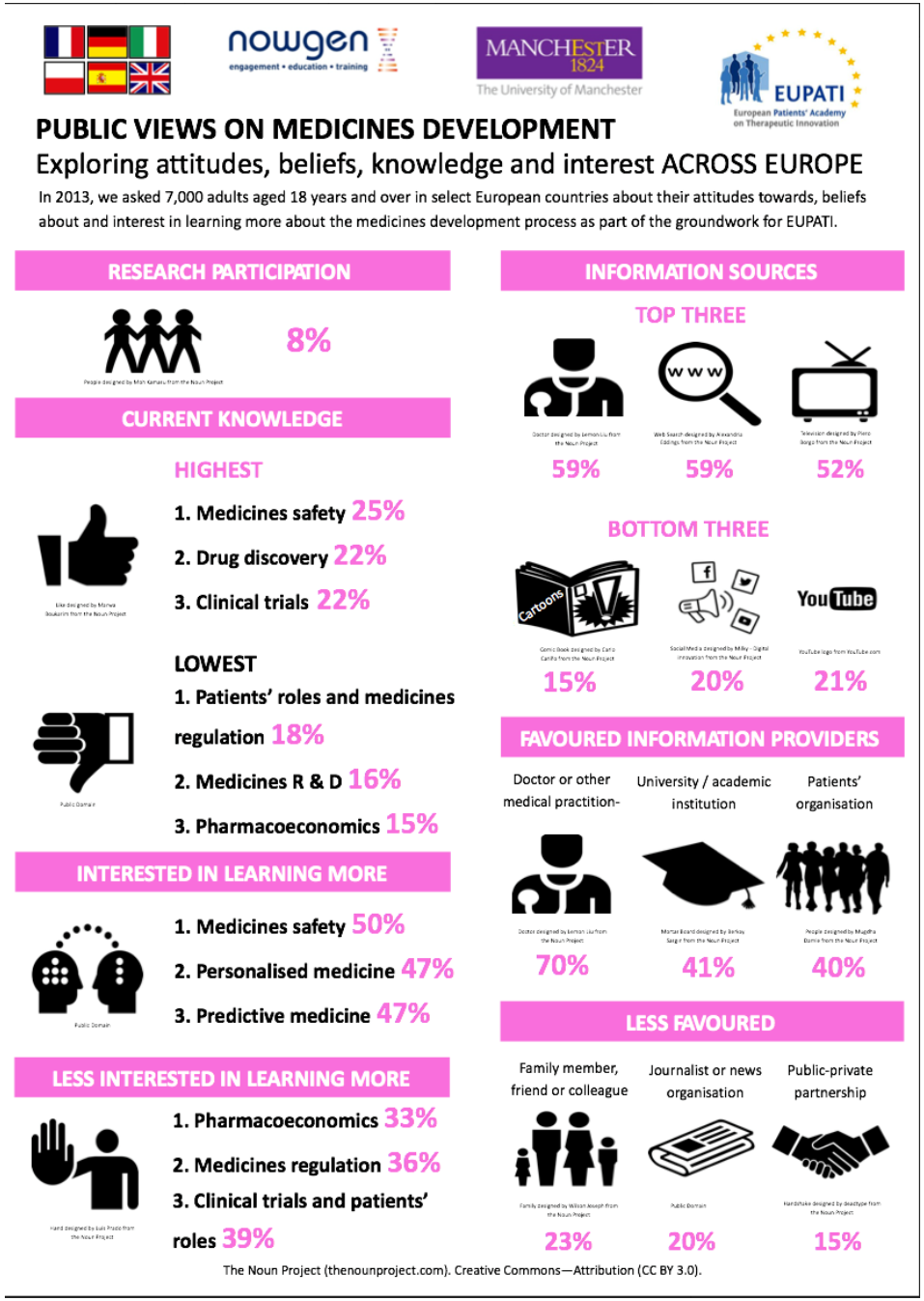
Design: Online survey of 6931 members of the public across Europe.

Methods: The survey formed part of a public omnibus

Strengths and limitations of this study

- The survey used a robust quota sampling method which ensured that a good cross-section of the adult population in each country was covered.
- Findings are mainly generalisable to Western

1. Topic Selection/ Research Prioritisation



EUPATI
European Patients' Academy on Therapeutic Innovation

EUPATI Driving Academic Research:

Understanding public views of medicines R&D across Europe identified

- Low knowledge of R&D
- Willingness to know more
- Support for more information from patient organisations, academia and medical professionals

1. UK Academic-led Patient-Centric Research Prioritisation

UK National Funders Driving Academia Partnership with Patient Advocacy Delivering Methodological Rigor and Robust Framework for PPI in prioritisation of medicines R&D

James Lind Alliance

Priority Setting Partnerships

THE COCHRANE COLLABORATION®

- Identify and prioritise treatment uncertainties which they agree are the most important for research
- JLA, brings key stakeholders i.e. patients, carers and clinicians together
- Goal to identify “Top 10” to ensure that researchers, and those who fund health research, are aware of what matters to both patients and clinicians.
- Funded by the National Institute for Health Research (NIHR)
- Literature reviewed and evidence gaps identified and research prioritised

James Lind Alliance Patient-Centric Research Prioritisation

James Lind Alliance
Priority Setting Partnerships

"The idea of bringing together clinicians, academics, patients, public and carers to discuss research priorities seems obvious – why shouldn't all those affected have a chance to jointly discuss frustrations about the things we don't know, and aspirations for the future?"

Richard Boards PPI Advisor involved in the Dental & Oral Health JLA Priority Setting Partnership

JLA and Multiple Sclerosis

James Lind Alliance
Priority Setting Partnerships

MS
Multiple Sclerosis Society

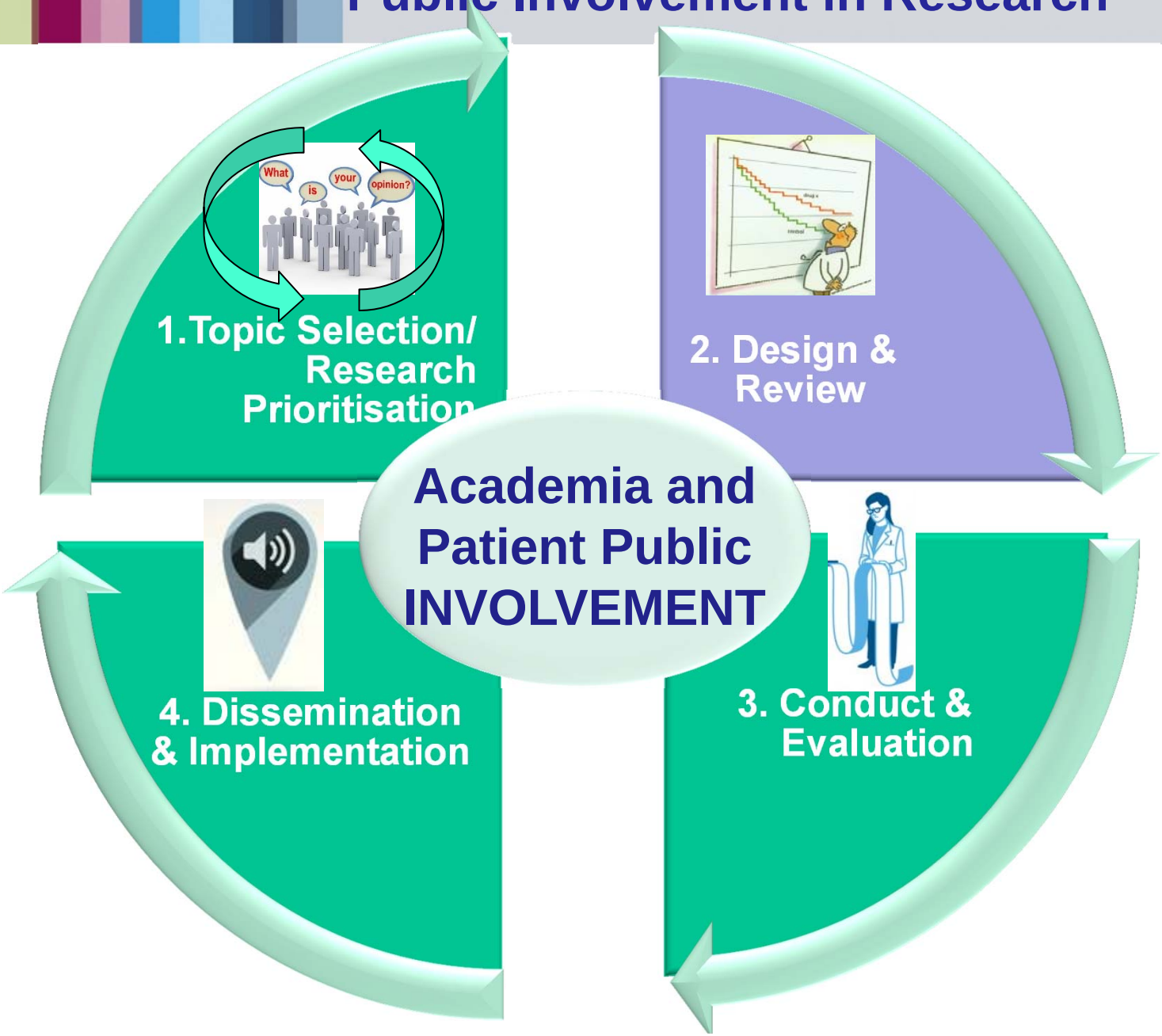
JANUARY/FEBRUARY 2014
www.mssociety.org.uk

Research Matters
The latest developments, innovations and achievements in MS research

Key document downloads

- MS PSP Protocol (pdf) (0.11 MB)
- Example of MS Interim Survey (pdf) (0.30 MB)
- MS PSP Poster (pdf) (0.54 MB)
- MS PSP Top 10 announcement (pdf) (0.57 MB)
- MS Research Matters Newsletter (reproduced with kind permission of the MS Socie
- Multiple Sclerosis PSP data sheet of uncertainties (pdf) (0.04 MB)

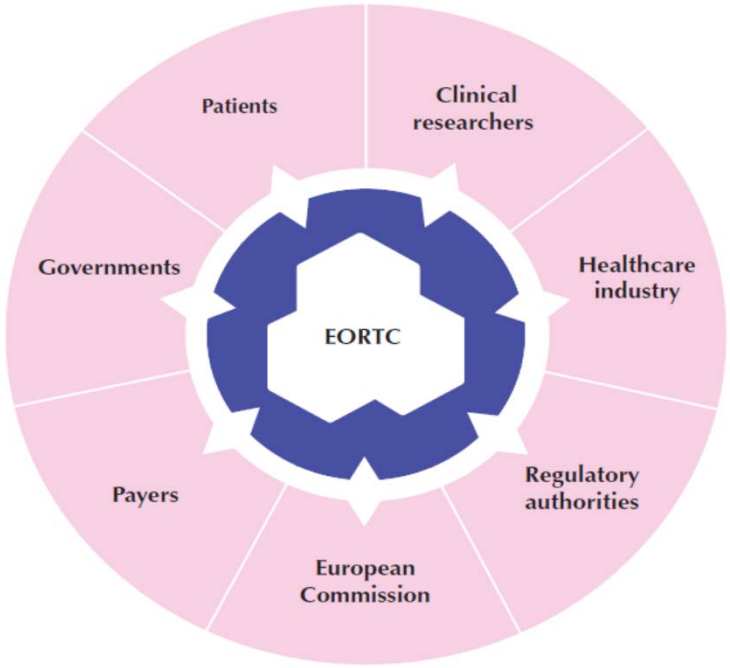
Academia examples of Meaningful Patient Public Involvement in Research



2. Review & Design of Research

Anastassia Negrouk & Stéphane Lejeune
EORTC, Belgium

EORTC experience with patient involvement in clinical research activities



Academic & Clinical Research

EORTC TODAY

- A private and non-profit cancer research organisation founded in 1962
- Headquarters based in Brussels, Belgium
- Core activities are related to the design and conduct of clinical trials across a Pan-European Network

- **46 trials open to patient entry, 207 active trials**
- **18 trials opened in 2015**
- 187,600 patients in databases, > 24,000 patients in follow-up
- 21 groups/task forces, 632 institutions & 125 collaborators
- 180 members in the HQ staff
- 442 publications in 2012-2014
- 34 different countries

2. EORTC Patient involvement – Review

2011

- Patient project concept
- Contact data base, www links, exchange of newsletters…
- Establishment of contacts with some patient organizations
  - Cancer specific: sarcoma, brain cancer
    (pilot random reviews of patient information, participation in group meetings)

2012

- Pilot reviews of Patient Information Sheets in UK and FR
- Patient member at EORTC International Review Board
- Exchange of speakers at conferences
- Joined EU projects: EUPATI

2014

- Biannual patient course (cancer clinical research): 2014 & 2016 -> 2018
- Review of patient information extended to protocols (19 reviews performed)
- *Ad hoc* participation in trial steering committees (e.g. SPECTAs - Screening Patients for Efficient Clinical Trial Access)

2016

- Review of trial concepts (5 concepts reviewed)
- Composition of patient panel – providing strategic advice

EORTC

2. EORTC Patient involvement –Review

Future Plans:

2017-2018

- Consolidate existing reviews, interactions & partnerships
- Optimize processes in place & increase communication and feed-back
- Extend project reviews to full protocols (feasibility perspective)
- Organize presentations for staff by patient advocates
- Continue to align with a wide range of patient advocacy groups

EUROPEAN CANCER PATIENT COALITION

EUPATI
European Patients' Academy on Therapeutic Innovation

EPF European Patients Forum

2. EORTC - Key challenges for international & multi-cancer research

- Patient organisations
- Representativeness
- Expertise
- Availability, reliability and timelines
- Communication
- Reward / retribution
- Expectations & estimation of added value

2. EORTC – Challenges of Working with Patient Organisations

Challenges:

- **Mission -> lobbying versus research**
- **Number -> EORTC database > 60 organizations**
- **Focus area -> sub-type**
- **Geographic coverage -> few are international**
- **Capacity & infrastructure - ad hoc support versus funded support**

2. EORTC Challenges - Ensuring Representativeness

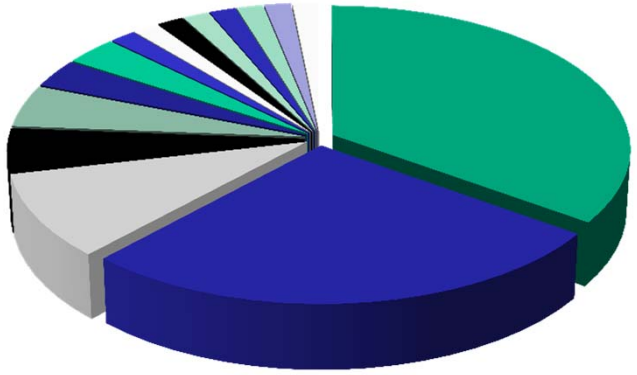
- Patient advocates versus patients & patient carers
  - **Consideration of the lived experience**
- Patient organisations can be driven by doctors
- Accessing the seldom heard ("*Hard to reach*")
- Patient activist / expert versus average patient
- "Usual suspects" & fair distribution of diseases and cultures

Patient Public "**Contributors**" rather than "**Representatives**"

2. EORTC Challenges - Accessing PPI Expertise

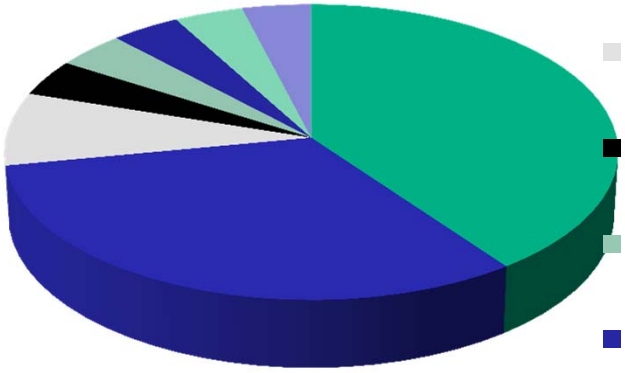
- Highly heterogeneous review outcomes
- Expertise / activists concentrated within countries with longer history of advocacy and more support available (UK, NL)
- Language barriers & variable IT skills
- EORTC experience is that very few feel comfortable with concept reviews

Volunteered reviewers at start: n=63



- Netherlands (22)
- United Kingdom (17)
- Belgium (6)
- Germany (3)
- Spain (3)
- France (2)
- Hungary (2)
- Bulgaria (1)
- Finland (1)
- Greece (1)
- Italy (1)
- Latvia (1)
- Lithuania (1)
- Portugal (1)
- Denmark (1)

Active reviewers: n=25/56*

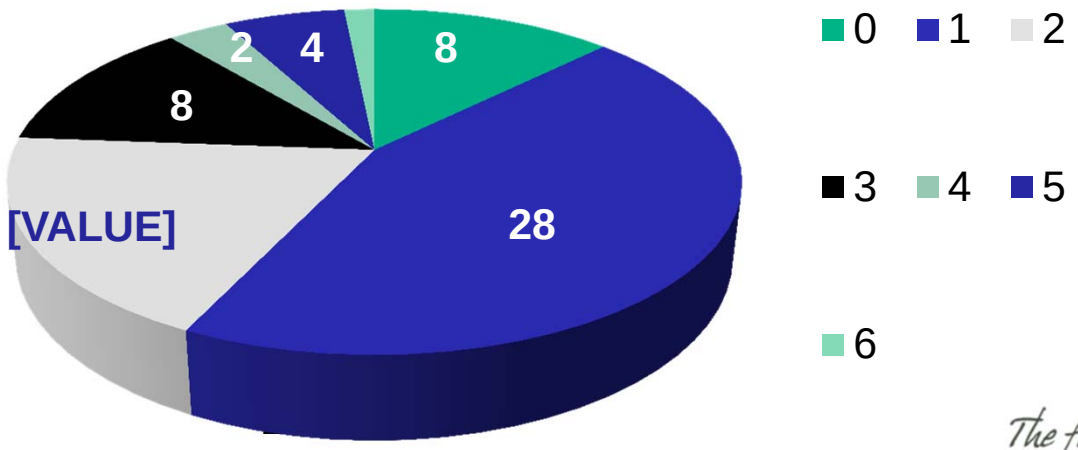


- United Kingdom (10)
- Netherlands (8)
- Germany (2)
- Belgium (1)
- Hungary (1)
- Italy (1)
- Latvia (1)
- Lithuania (1)

2. EORTC Challenges: Availability, reliability & timelines

- **Projects unequally distributed in the year**
  - rush times prior to summer and X-mas
- **Unequal number of projects per cancer type**
- **EORTC review timelines: max 4 weeks**
  - 2-3 weeks left for reviewers
  - 2 step process

Frequency of contact per reviewer



2. EORTC – Challenges in Communication

- Different communication style
  - high rate of “no reply”
  - some may not check their inbox regularly, fail to dispaly “out of office”…
  - change in e-mail without any way to have the new one
  - remote communication is probably not the best option -> F2F work better (?funding and timelines…)
- Requires involvement of specifically instructed staff
  - lay language communication
  - frequently communication via private phone/mail
  - probability of recurrence / illness episodes
- Interface between highly specialized community & benevolent contributors

2. EORTC - Reward/retribution

- Refund of travel and expenses (if F2F)
- EORTC believes honorarium is not appropriate as it may create conflicts of interests or other types of bias
- Other types of reward:
  - Acknowledgement? Some would prefer not to be named…
  - Recommendations in the scope of patient advocacy work?
  - Privileged access to courses and events?
  - Regular feed-back?
- How to keep reviewers motivated?

2. EORTC -Expectations & added value

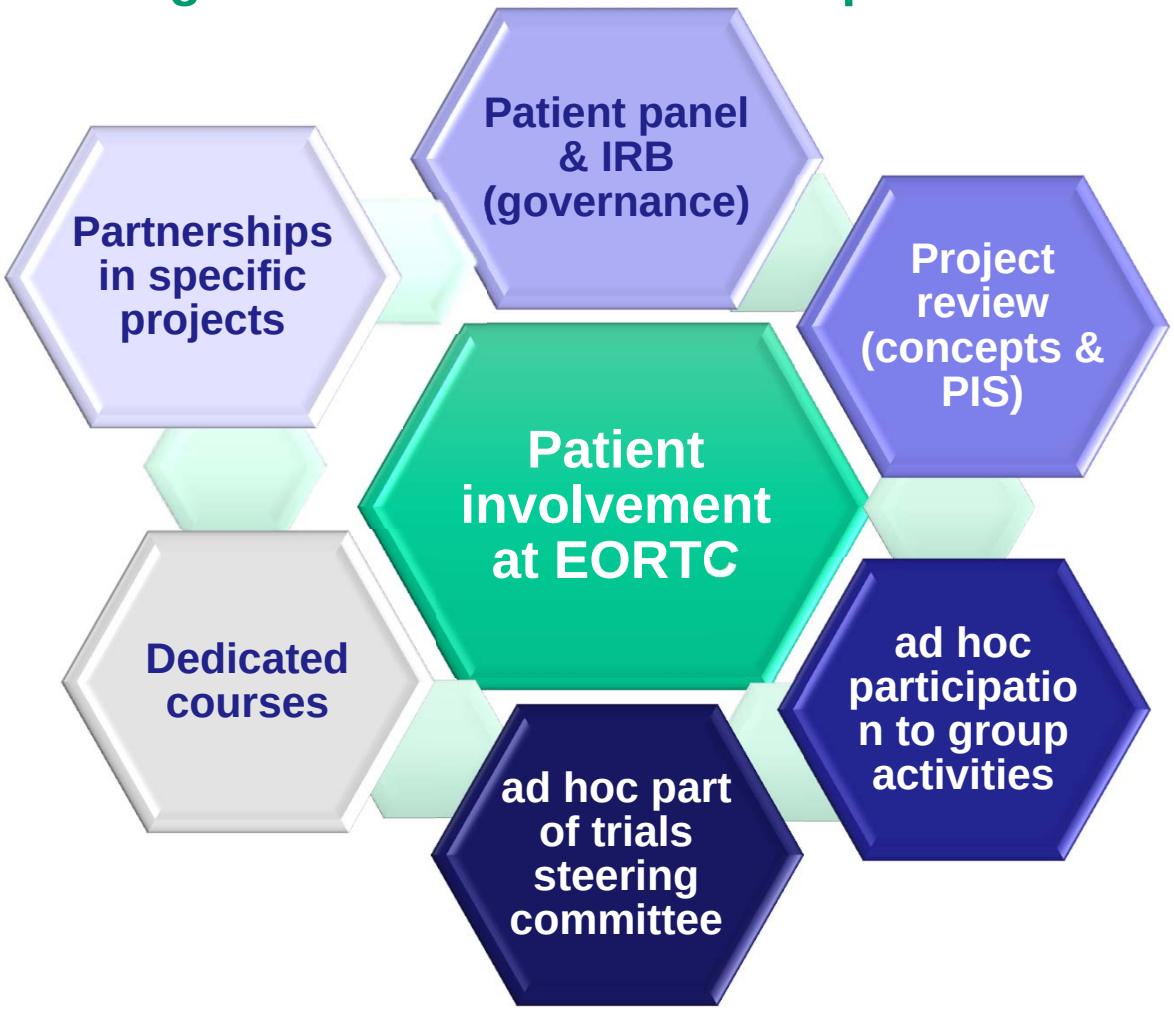
- **Need to clearly scope expectations**
  - introductory documents for reviewers
  - review form is an asset
- **Is patient involvement expected to be scalable to become part of SOPs subject to audit and inspection?**
- **What shall constitute a relevant comment / contribution?**
  - relevant & pertinent remark?
  - are “out of scope” comments of the most value?
- **Can we measure added value?**

EORTC - Take home messages

- Mutual learning curve -> valuable to exchange experiences
- Patient voice – new type of stakeholders
- Need to have more consensus on which kind of review for which purpose and by whom…
- Core funding makes all the difference

2. Conclusions of EORTC

- EORTC Committed to Patient –Centric approach
- Developing a full spectrum of patient involvement at EORTC
- Challenges being overcome to increase impact



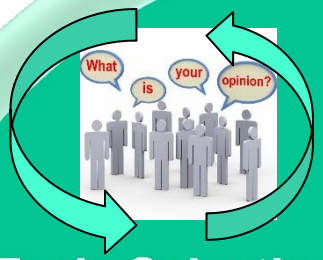
All UK Government Funded Clinical Research Expects/Mandates PPI

EUPATI-UK Aligns to National Commitment to Effective PPI:

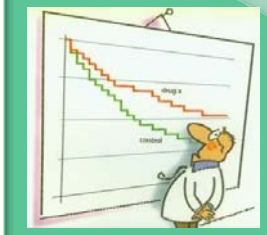
No research about us without us –
Patients at the core of medicines R&D

- To empower patients and the public to be effective advocates, advisors and contributors in medicines R&D.
- To deliver effective PPI within medicines research (including medical innovation in preclinical and clinical research) to enable the delivery of patient-centered health research and development in the UK

UK Demonstrator of Meaningful Involvement



1.Topic Selection/ Research Prioritisation



2. Review & Design

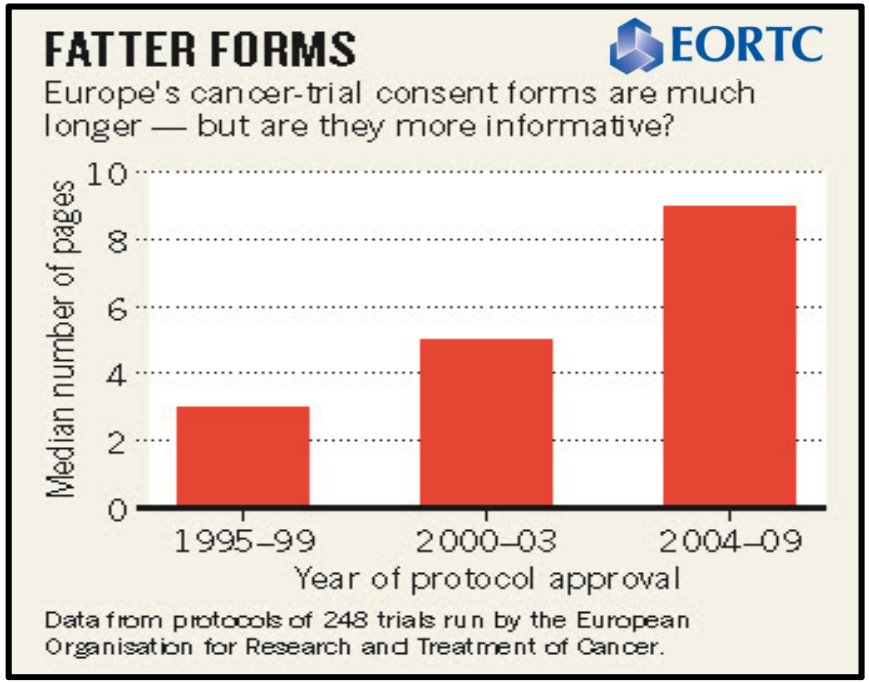
Academia and Patient Public INVOLVEMENT

3. Conduct & Evaluation

4. Dissemination & Implementation

3. Academics working to improve the trial conduct – Informed Consent

- **Survey of information sheets for cancer trials, by the European Organisation for Research & Treatment of Cancer**



What do Patients think?

'Lengthy, complicated documents leave many clinical-trial participants in the dark about the risks they face.'

D Cressey. Nature 2012; 482: 16.

3. Academics working to improve the trial conduct – Informed Consent

Do (potential) participants really understand what they're agreeing to?

- **Consent:**
  - Important information not stated & patient understanding not checked *(Jenkins et al 1999)*
- **Information sheets:**
  - Written at the 'college graduate' level *(Paasche-Orlow et al 2003)*
  - Understanding particularly poor in older and less educated patients *(Sugarman et al 1998)*
  - Risks and benefits not understood well *(Cox et al 2006)*

"Personally, I wouldn't have signed it."

3. Academics working to improve the trial conduct – Informed Consent

The Importance of Health Literacy

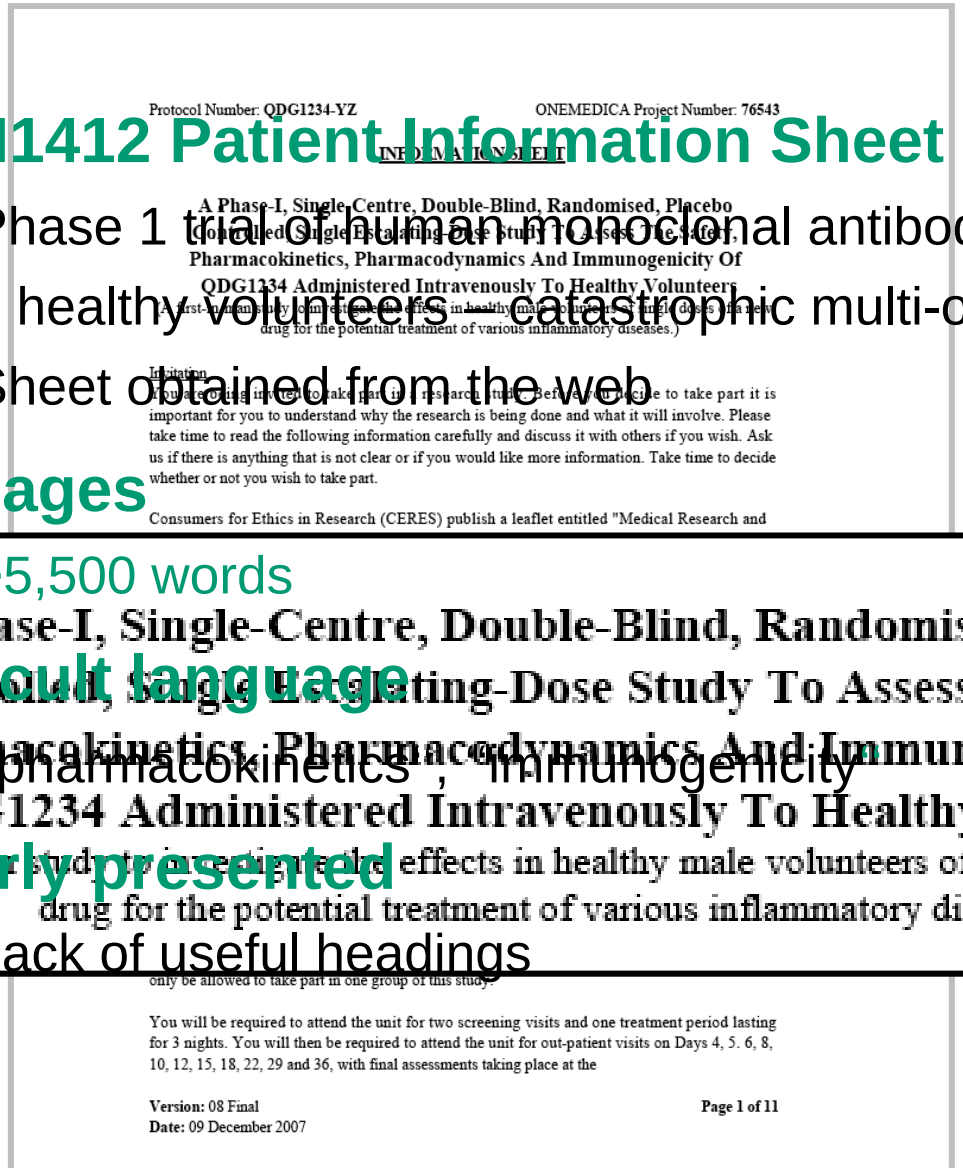
- **Moser report *(Department of Education,* 1999):**
  - **1 in 5 UK adults not “functionally literate“**

- **1958 national birth cohort study *(Bynner & Parsons,* 1997):**
  - **At age 37, 13% have “low literacy“ and**
  - **An additional 6% have “very low literacy“**

- **Is information a tool to narrow or widen health inequalities?**

Lessons learnt from the TGN1412 Patient Information Leaflet

- **TGN1412 Patient Information Sheet**
  - Phase 1 trial of human monoclonal antibody
  - 6 healthy volunteers – catastrophic multi-organ failure
  - Sheet obtained from the web
- **11 pages**
  - >5,500 words
- **Difficult language**
  - "pharmacokinetics", "immunogenicity"
- **Poorly presented**
  - Lack of useful headings



Protocol Number: QDG1234-YZ ONEMEDICA Project Number: 76543

INFORMATION SHEET

A Phase-I, Single-Centre, Double-Blind, Randomised, Placebo Controlled, Single Ascending-Dose Study To Assess The Safety, Pharmacokinetics, Pharmacodynamics And Immunogenicity Of QDG1234 Administered Intravenously To Healthy Volunteers

(A first-in-man study investigating the effects in healthy male volunteers of single doses of a new drug for the potential treatment of various inflammatory diseases.)

Invitation

You are being invited to take part in a research study. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Consumers for Ethics in Research (CERES) publish a leaflet entitled "Medical Research and

only be allowed to take part in one group of this study.

You will be required to attend the unit for two screening visits and one treatment period lasting for 3 nights. You will then be required to attend the unit for out-patient visits on Days 4, 5. 6, 8, 10, 12, 15, 18, 22, 29 and 36, with final assessments taking place at the

Version: 08 Final **Page 1 of 11**
Date: 09 December 2007

3. Academics working with patients to improve the trial conduct – Informed Consent

ORIGINAL

Newland Hill NHS
NHS Foundation Trust

Newland Hill NHS Foundation trust,
Assisted Conception Unit,
Newland Hill Hospital,
London, NW16 7BJ.
Tel 01234 149688
Fax 01234 149655

Poor Responders Intervention Trial

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research study. Before you make your decision, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. You may want to talk to others about the study before taking part.

Part 1 tells you the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study.

Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Part 1

What is the purpose of the study?

There are three commonly used regimens used to suppress the pituitary hormones during In Vitro Fertilisation (IVF). The purpose of this research is to find out which of these is the most effective for women who have shown a poor response in their previous treatment cycle(s). There is currently no evidence to say which gives the best outcome.

It is necessary during IVF treatment to control the reproductive cycle. In order to do this drugs are used to suppress the reproductive hormones released by the pituitary gland in the brain. These hormones are the Follicle Stimulating Hormone (FSH) and the Luteinising Hormone (LH). Both these hormones are stimulated by the Gonadotrophin Releasing Hormone (GnRH).

There are two types of drugs which suppress the pituitary hormones. The first is a GnRH agonist, called Nafarelin. An agonist is a drug which mimics the action of a naturally occurring substance in the body. Nafarelin activates the pituitary just like the GnRH in the body, but while the GnRH triggers the release of hormones by repeated on/off pulses, Nafarelin in IVF treatment delivers a long, sustained burst which keeps the pituitary in the 'off' mode.

The second drug is a GnRH antagonist, called Cetrorelix. An antagonist is a drug which opposes the action of a naturally occurring substance in the body. In this way, Cetrorelix prevents the release of pituitary hormones.

RE-DESIGNED

Participant Information Sheet

Newland Hill NHS
NHS Foundation Trust

Study of IVF Treatments for Women where Previous IVF has not been Successful

We invite you to take part in a research study.

- Before you decide whether to take part, it is important for you to understand why the research in being done and what it will involve.
- Please take time to read the following information carefully. Discuss it with friends and relatives if you wish.
- You are free to decide whether or not to take part in this trial. If you choose not to take part, this will not affect the care you get from your own doctors.
- Ask us if there is anything that is not clear or if you would like more information.

Important things that you need to know

- We want to find the best way to treat women who have not responded well to previous IVF.
- We are testing the use of two different medicines as part of IVF treatment, which are Nafarelin and Cetrorelix.
- Nafarelin can be used in two different ways, so the study has three different groups or treatment options.
- One medicine used in the study can cause side-effects, but they are short lived.
- This study fits into your normal treatment, so there are no extra clinic visits or scans.
- You do not have to pay for Nafarelin or Cetrorelix, but the other medicines used in IVF may have to be paid for.
- You can stop taking part in the study at any time.

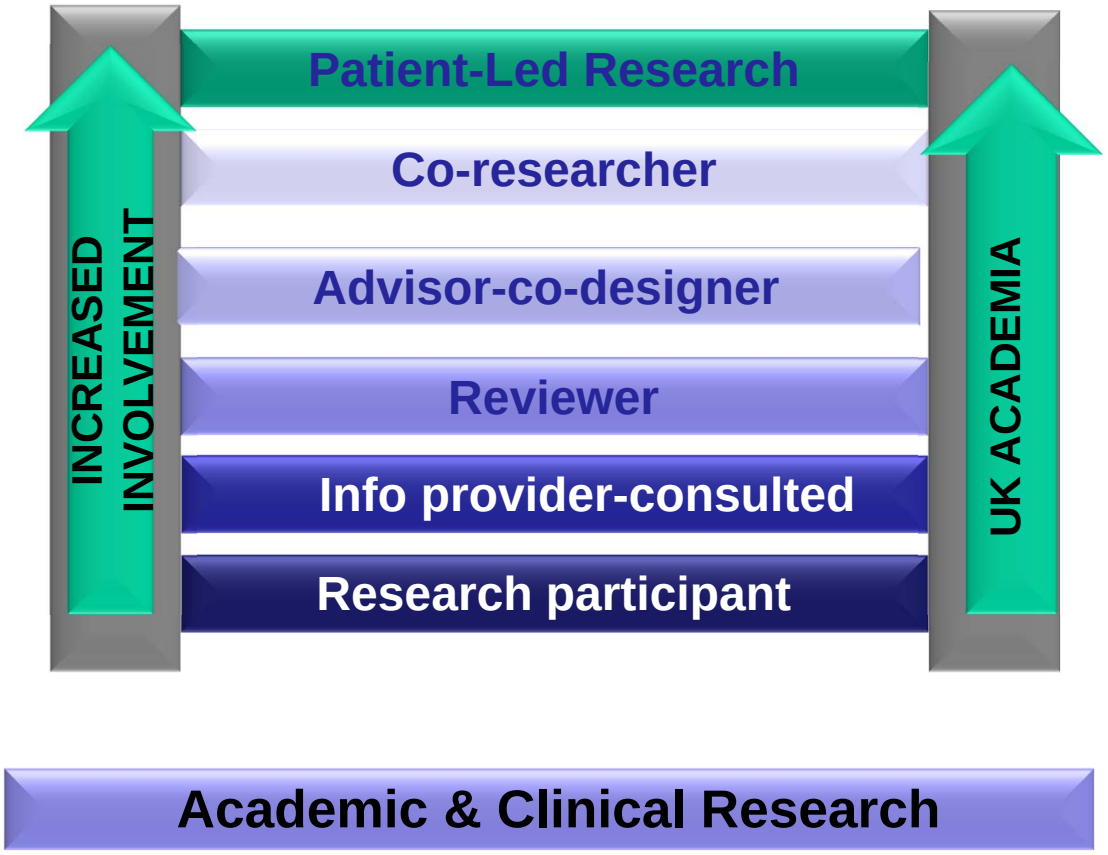
Contents

How to contact us

If you have any questions about this study, please talk to the doctors who organise it: Dr Stoke or Mr Prestwich on **01234 149 688**.

Courtesy of Dr Peter Knapp
University of York
peter.knapp@york.ac.uk

2. Review & Design
3. Conduct & Evaluation



The Leeds Teaching Hospitals NHS Trust

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Could you help dental Research?

Your views are important to us
and would help shape our future research.
We really want to hear from you if you have opinions or experiences of oral or dental health issues (perhaps as a patient, family member, or carer) and could assist us by joining the Leeds Oral Health Patient and Public Involvement Group

SMILE AIDER

Stakeholder Meaningful InvoLvement & Engagement Aiding Dental Research

PLEASE CONTACT

For more information and enquires:-

Jenny Boards
School of Dentistry
Telephone: 0113 3436197
Email: dentcru@leeds.ac.uk

Dental Translational & Clinical Research Unit

The Leeds Teaching Hospitals NHS Trust

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SMILE AIDER

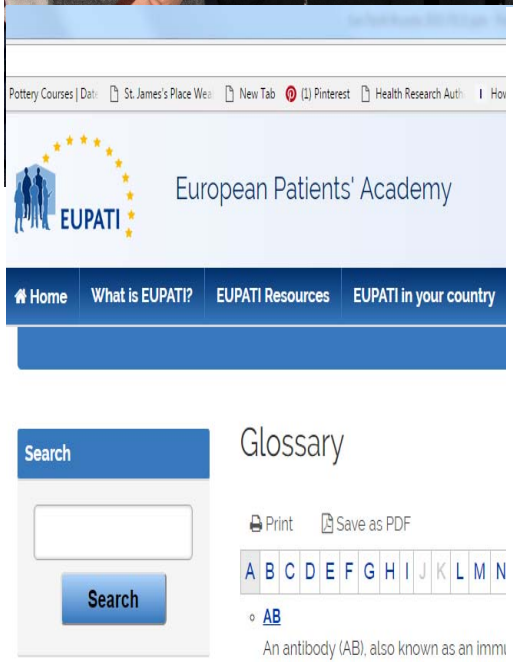
Stakeholder Meaningful InvoLvement & Engagement Aiding Dental Research

What you can expect if you join the SMILE AIDER group?

As a member of SMILE AIDER you can help ensure our research is:

- Patient-centred research
- Address topics of interest to patients
- Is patient-friendly to those taking part in studies
- Will maximise patient benefits and improve NHS treatment & care

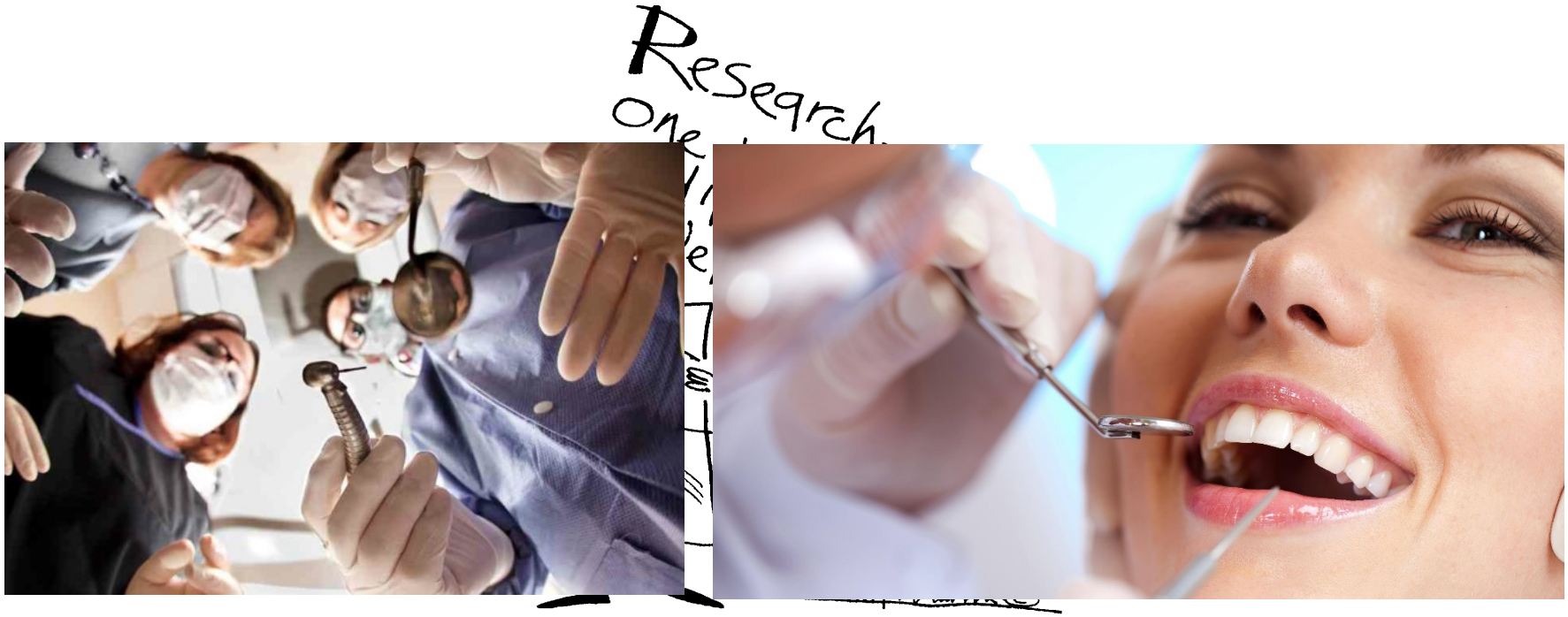
SMILE AIDERS PPI FORUM
Diverse, inclusive & informed



The EUPATI Toolbox on Medicines Research and Development is LIVE!

All Academic Clinical Dental Research in Leeds is Reviewed by the SMILE AIDER PPI Forum

Ensures research has patient relevance and asks the right question



PPI in Designing a Research Study

Questions asked in Designing a Clinical Study

Why?

When?

How?

What do patients think?

Are we asking the right question to improve the health and quality of life for patients?

2. Review & Design
3. Conduct & Evaluation & 4. Dissemination

SMILE AIDER PPI Forum
Achieving effective PPI in Dental Research

- All Clinical Research is reviewed by PPI Forum
  - Early Concept, Grant applications, Protocols
- They input to research questions and design
- Review operations/ & logistics
- Join the trial steering committee for further input to conduct & evaluation
  - Patient literature & ethics submission
- Support innovation in dissemination

2. Review & Design
3. Conduct & Evaluation & 4. Dissemination

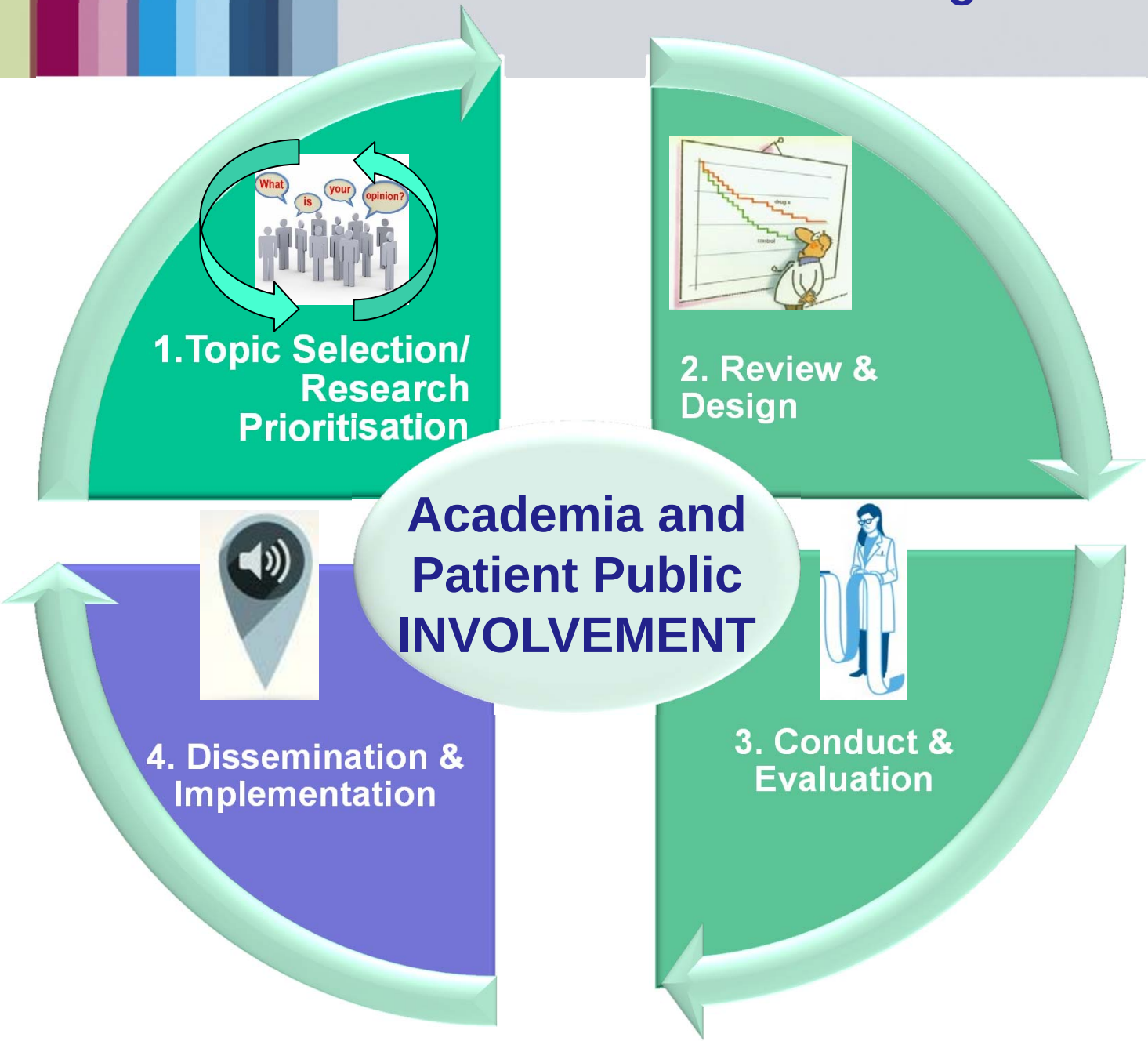
SMILE AIDER: Achieving effective PPI in Dental Research

User involvement achieved across the research cycle ensures:

- **different perspectives heard**
- **research priorities identified by clinicians are also important and relevant to their patients**
- **outcomes that are important to patients are measured**
- **improved research design**
- **improved trial logistics**
- **access to patients - via peer networks**
- **access 'seldom heard'** [hard-to-reach'] **patient groups**
- **effective dissemination**

Improved research that addresses: patient needs, achieves recruitment & retention, delivers to target & maximises patient benefit

UK Demonstrator of Meaningful Involvement



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The COHESION Pilot

Collaborative Hub 4 Engagement across arts and Science to aid Impact and Dissemination.

Professor Sue Pavitt.
Dr Peter Day & SMILE AIDERS PPI Forum
School of Dentistry

Nigel Townsend & Judith Johnstone
Theatre of Debate

Professor Alice O'Grady & Dr Rebecca Collins
School of Performance & Cultural Industries

David Cooper & Pupils
Batley Girls' High School

School of Dentistry
Faculty of Medicine and Health

UNIVERSITY OF LEEDS

Don't Smile - A Love Story with a Dental Theme!

Using Theatre and Debate to Disseminate Research To At-Risk Seldom-Heard Adolescents in Areas of Social Deprivation and High Oral Health Inequality.

Sue H. Pavitt[1], Jenny Boards[1], Peter F. Day[1], Alice O'Grady[2], Rebecca Collins[2], Nigel Townsend[3], Jonathan Barber[1], Sophy Barber[1], Kate Kenny[1], Jenny Owen[1], Wendy Thompson[1], Kara Gray-Burrows[1], Timothy Zoltie[1], Ben Douglas[1], Katie Maddison[2], Harry Duff-Walker[2], Katie Mahon[2], Lily Craig[2], David Cooper[4], Ariba Syeda[4], Humairaah Wazah[4] and SMILE AIDER PPI Forum[1]

1. School of Dentistry, University of Leeds, Leeds, LS2 9LU UK
2. School of Performance & Cultural Industries, University of Leeds
3. Theatre of Debate, London, UK
4. Batley Girls' High School, Windmill Lane, Batley, WF17 0LD

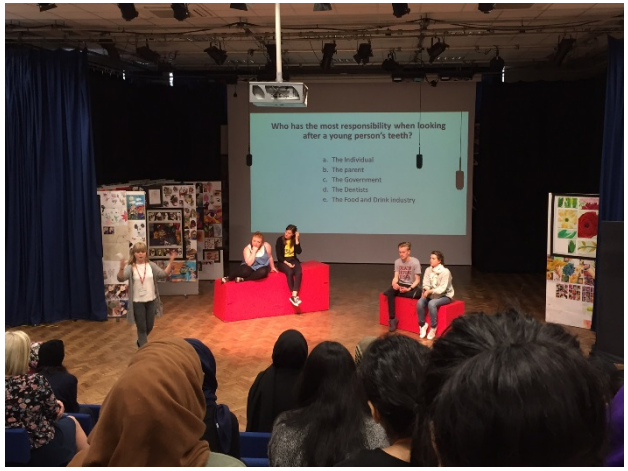
Health Need:

In Yorkshire, 45% of 12-year-olds have rotten teeth resulting in pain, lost schooling and low self-esteem; it is correlated with social/health inequality. Whilst largely preventable, reaching those most vulnerable in deprived areas is challenging. Disadvantaged teenagers intrinsically don't liketo be told what to do.

Purpose:

Don't Smile was inspired to test if using theatre might impart knowledge non-judgmentally, allow debate and improve oral health awareness in at risk adolescents.

Academia Driving Innovation
Don’t Smile - Results



- TOD Facilitator initiated a poll relating to oral health awareness and opinions of the school pupils
- Following the play she revisited for a change in response
- Facilitated a debate between the audience and the actors in character providing opportunity for the audience to ask questions about the research.

Results

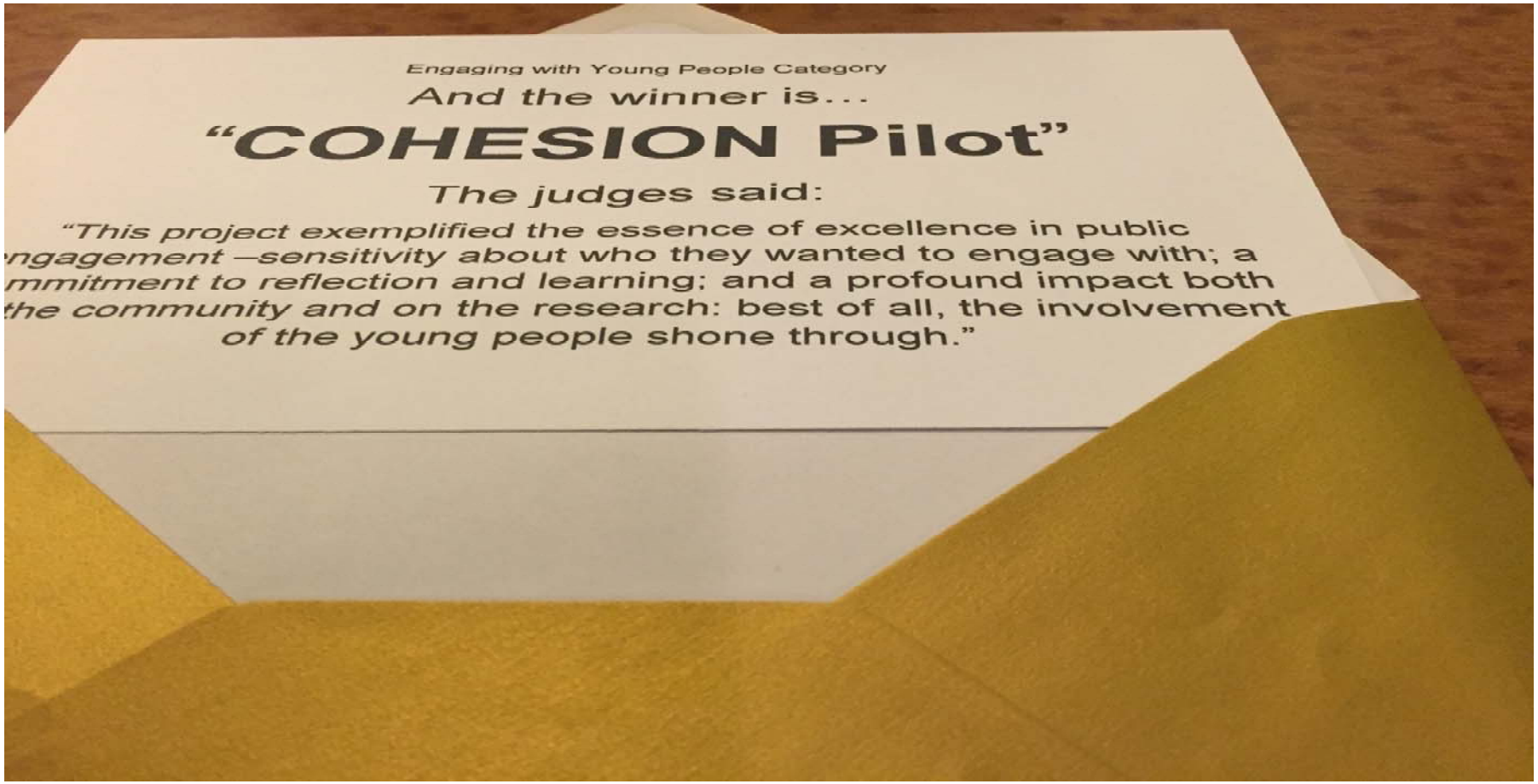
REACH: audiences of vulnerable teenagers from areas of worst oral health inequalities

Questionnaire were completed and analysed:

- The embedded oral health message ‘dealing with dental trauma’ was understood by 100% audiences.

- The play rated excellent/ very good with 95.5% saying they would like to see more plays on aspects of oral health/dentistry.

Category: Engaging with Young People



The NCCPE Award Ceremony

NCCPE
Engage Competition 2016
Celebrating Excellence

Levels of Involvement

ENGAGEMENT

Education / Knowledge transfer to Public

CONSULTATION

Lay views used to inform decision-making

PARTNERSHIP/ COLLABORATION

Active collaboration between 'professionals' and lay people

USER LED RESEARCH

Focus of power, initiative & decision making is with service users

Increasing empowerment of PPI contributors within the research process

Unexpected Outcome: User-led research

RAISED in Yorkshire: Research **A**ctivity **I**n **S**chools **E**valuating **D**ental health

RAISED in Yorkshire: RiY Student Research Fellows

UK Seldom Heard – User Led Research

- Oral Health Behaviour
  1. What Oral hygiene projects are bring used in the home
     - Shared brushes, electric vs manual, floss, toothpaste, mouth rinse
  2. How do pupils brush their teeth
     - How much tooth paste – a pea size or a strip along the brush
     - Spit or rinse on completion
- Oral Health Surveys
  3. Dental Health Survey
  4. Anxiety

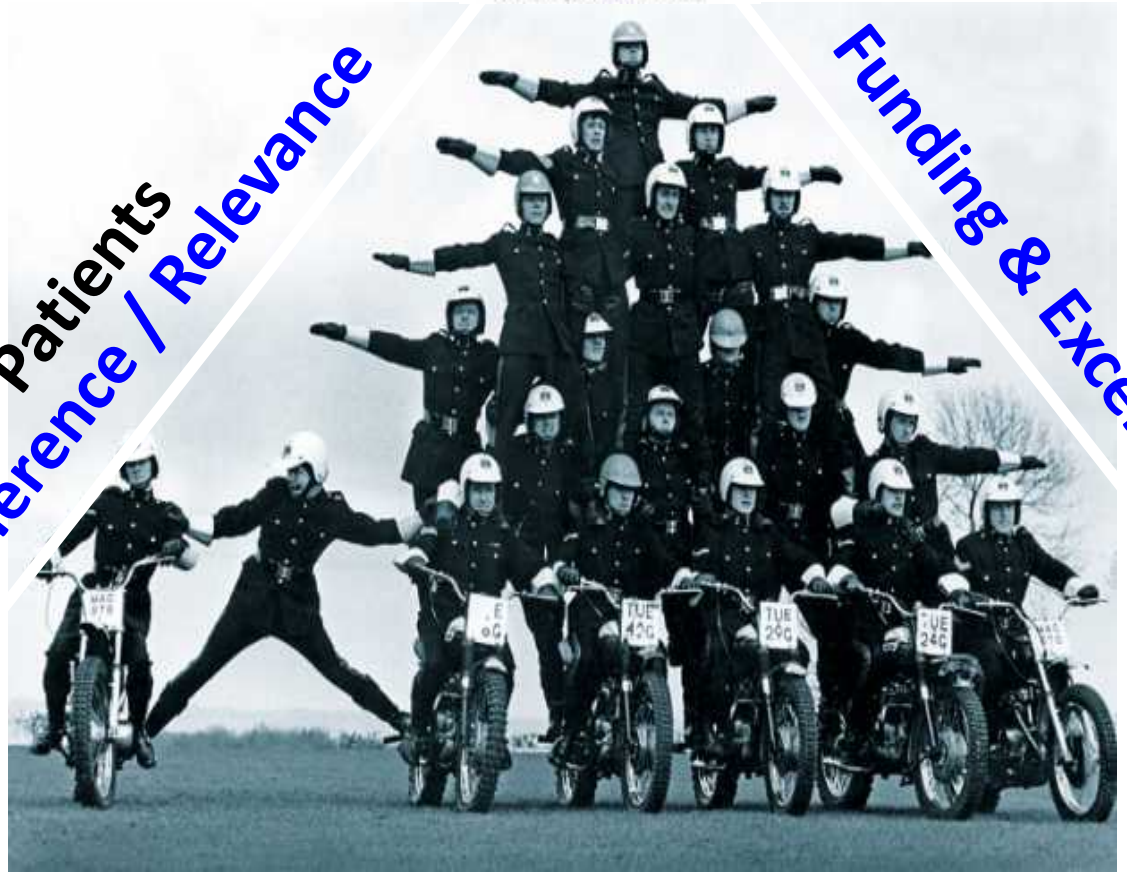
DELIVERY OF PATIENT CENTRIC RESEARCH

Building effective Partnerships

EUPATI
European Patients' Academy on Therapeutic Innovation

Patients

Coherence / Relevance



Funding & Excellence

Industry

Innovation & Evidence-based Approach

Academia

EUPATI-UK – True Tri-partite partnership
Learning to embrace its wonderful fellows