



HRI

health research institute

Participation in primary healthcare: The relevance of participatory health research

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OLLSCOIL LUIMNIGH

Presentation Outline

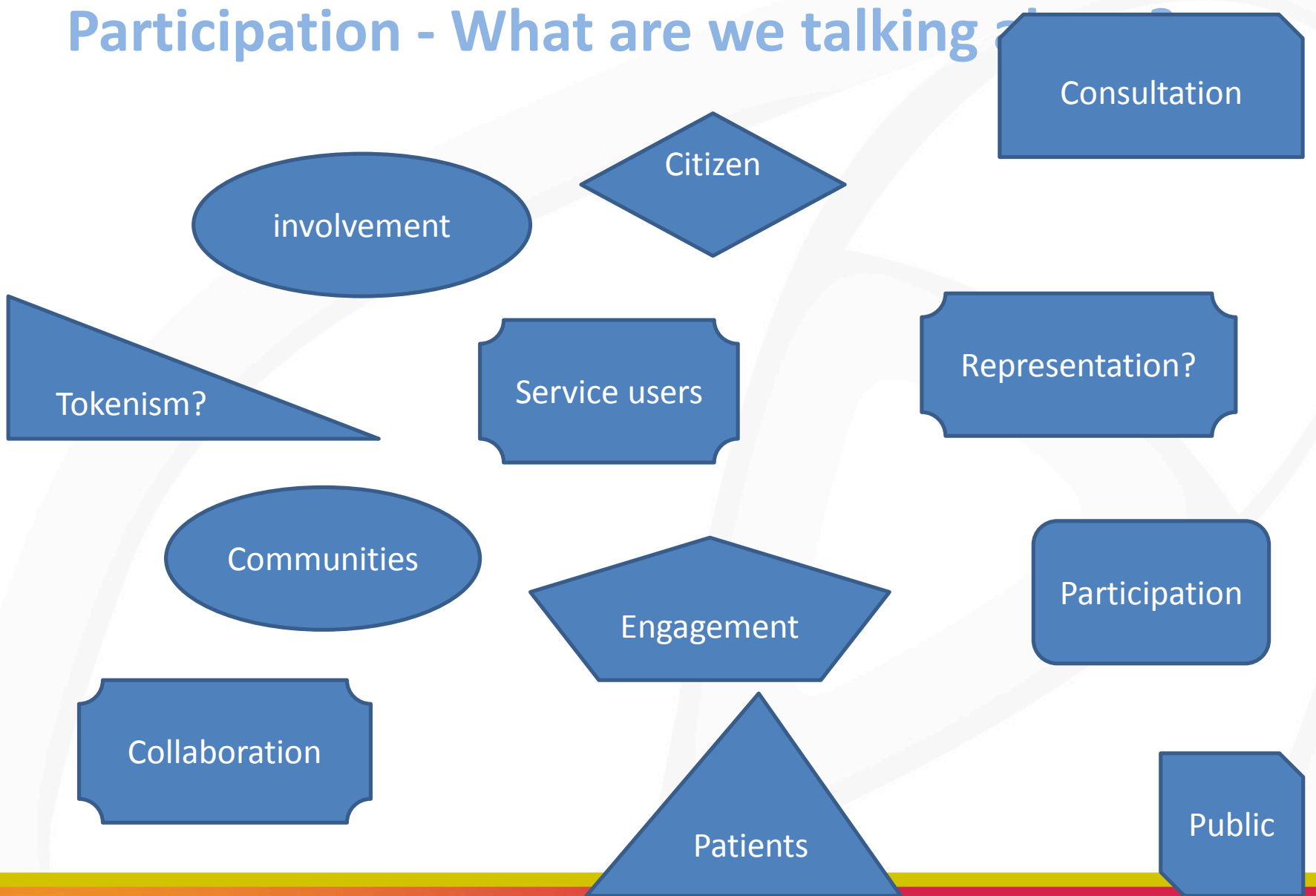
Part I

- Participation in health
- Participatory health research
 - Meaningful partnerships
 - Dialogues, structures and spaces

Part II

- Migrants' participation in the adaptation of primary care services

Participation - What are we talking about?



Health Promotion

Health promotion is the process of enabling people to increase control over, and to improve, their health.

1. Build healthy public policy
2. Create supportive environments for health
3. Strengthen community action for health
4. Develop personal skills
5. Re-orient health services

WHO, Ottawa Charter, 1996

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Primary Health care

People have the right and duty to participate individually and collectively in the planning and implementation of their health care.

Effective primary healthcare requires and promotes maximum community and individual self-reliance and participation in the planning, organization, operation and control of primary health care.

(WHO, Alma Ata, 1978)

Public and Patient Involvement in research: doing research with (not on) people



Guidance on PPI activities in Ireland

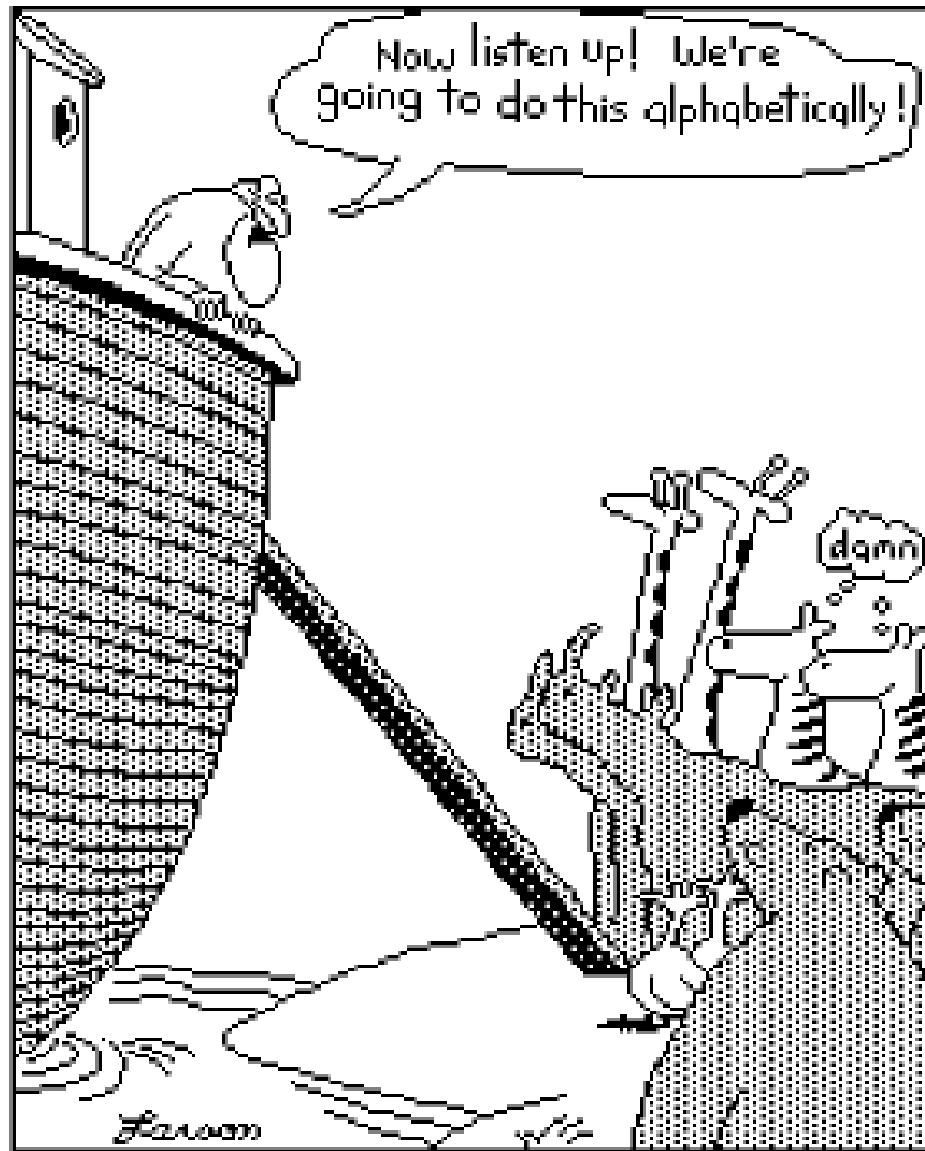
Issues of participation, power and

- Range of possible PPI activities (& they can be done at a range of levels)
 - **As co-applicants on a research project**
 - Involvement in identifying research priorities (at institutional or charity level)
 - **As members of a project advisory or steering group.**
 - Assisting with the developing of patient information leaflets or other research materials
 - Carrying out the research
 - Dissemination and implementation of the research
- **All approaches are valid and the level of PPI should be determined on a case by case basis for a particular project or initiative.**

...who
have
shaped
the
project

...with equal
involvement in
decision making?

Who decides
and on what
basis?



Dialogues for transformation



We need to create structures and spaces for dialogues for health research

Resources

- **Participatory health research (PHR)** to reduce health inequities
 - *Research is not done “on” people as passive subjects providing “data” but “with” them to provide relevant information for improving their lives. **The entire research process is viewed as a partnership** between stakeholders which may include academic researchers; professionals in the fields of health care, education and social welfare; members of civil society; policy makers and others.* [International Collaboration for Participatory Health Research, Position Paper No. 1 (2013)
<http://www.icphr.org/>



Resources

- **Participatory Learning and Action research** (Chambers, 1994; O'Reilly de Brún and de Brún, 2010)
 - Is a practical approach to research with diverse groups where asymmetries of power may exist
 - Brings diverse stakeholders together to engage in a process of shared, enhanced learning to identify solutions to shared problems
 - Promotes reciprocity mutual respect, co-operation and dialogue in research encounters within and across diverse stakeholder groups
 - Has a range of techniques for generating and analysing data that are inclusive, user-friendly and democratic

Participatory methodologies can be used to frame interactions in research spaces



Part II

Migration



Linguistic and cultural diversity in Ireland

Population Usually Resident and Present in the State who Speak a Language other than English or Irish at Home (Number) by Birthplace, Age Group, Language Spoken and Census Year

	2011
All countries excluding Ireland	
All ages	
Polish	108,953
French	18,630
Lithuanian	28,816
German	12,501
Spanish	10,383
Russian	18,850
Romanian	16,513
Chinese, nec	12,503
Latvian	11,944
Portuguese	10,468
Arabic	8,958
Italian	6,720
Yoruba	7,981
Slovak	8,872
Other stated languages (incl. not stated)	98,789

CSO (2011) . Available from:

<http://www.cso.ie/px/pxeirestat/Statire/SelectVarVal/Define.asp?Maintable=CDD46&PIanguage=0>

Migrants' involvement in health

**Public policy fora
(de Frietas and Martin, 2014)**

**Primary care service development
(Tierney et al., 2017; McEvoy et al., under review)**

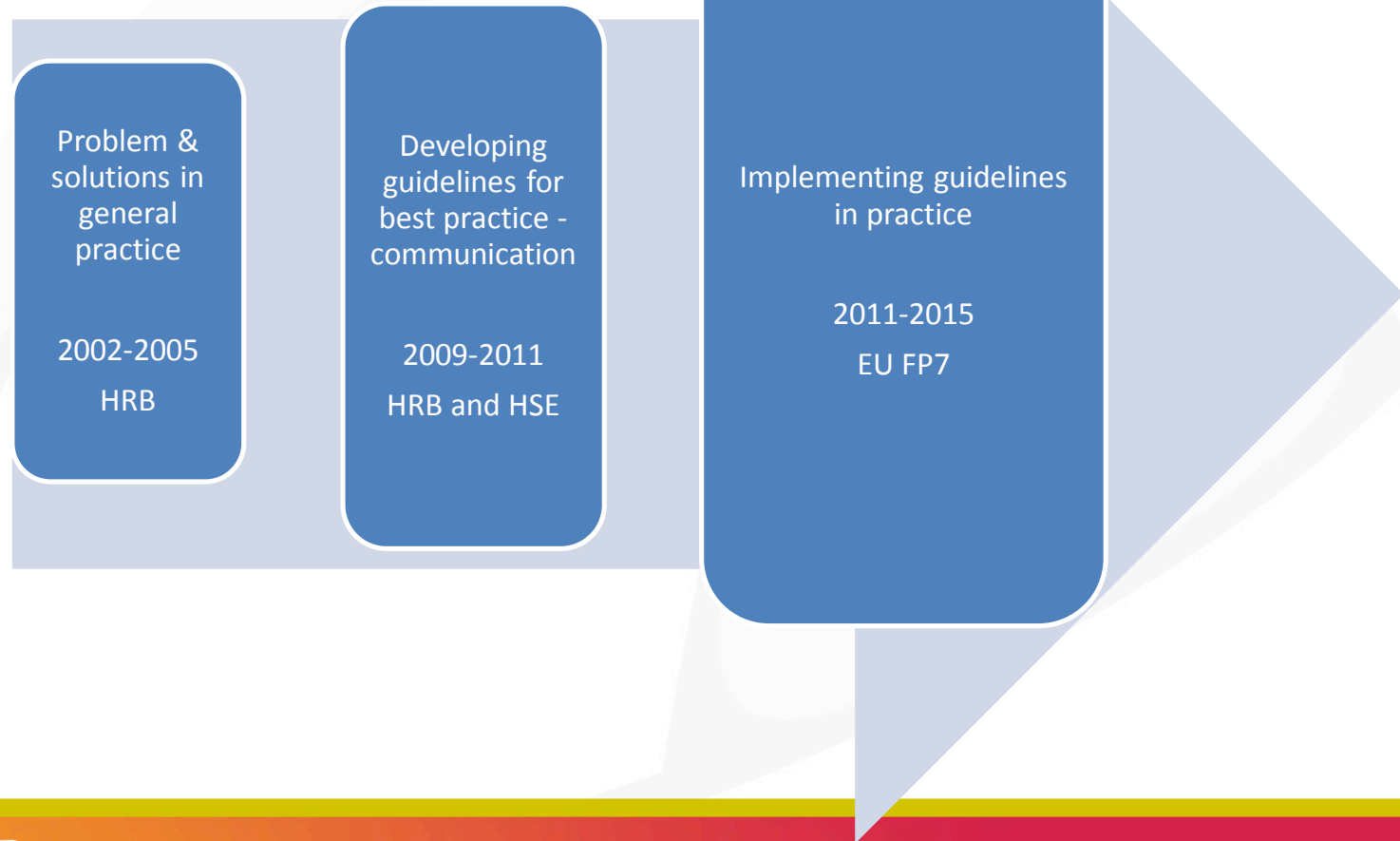
**Health research
(O'Reilly-de Brun et al., 2015)**

Absent

'Hard-to-reach'

Easy-to-ignore?

Involving migrants in health research to adapt primary care services





EU FP7 RESTORE project

Implementation work in primary care settings

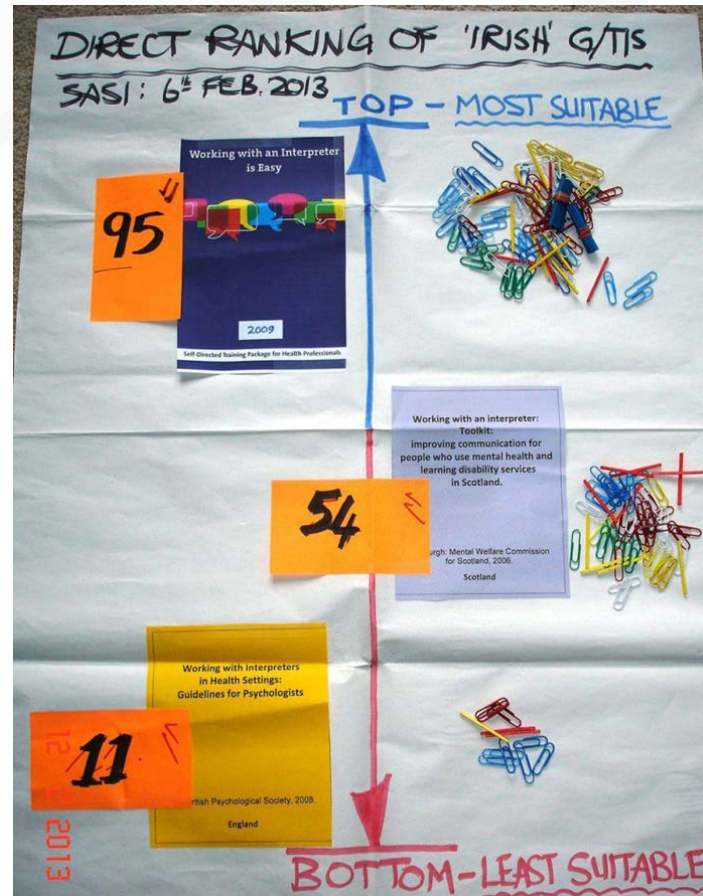
- Analysed healthcare and policy context in each country (O'Donnell et al., 2016)
- Identified relevant Guidelines and Training Initiatives (de Brún et al., 2015)
- Migrants and other stakeholders selected a Guideline or Training Initiative for implementation in their local primary care setting (Lionis et al., 2016)



- Completed 28 PLA style focus groups
- Sept 2012 & May 2013
- Austria, England, Greece, Ireland, the Netherlands



PLA Direct Ranking Chart



PLA: A safe space

- *Great feeling of safety within the group. I felt comfortable to express my views and suggestions* IRL Migrant and Community interpreter
- *It is not necessarily always the case to work with different professionals in this relaxed way* AUS academic

PLA: Democracy in action

- *20 votes rather than one – very interesting! Colour-coded voting [was] excellent. [A] visual as well as numeric result!*

IRL Health service planner

- *The best part for me was the voting process, everything was equal* GR Migrant

PLA: Power and ownership

- *It gave me a feeling of importance to participate here* AUS Migrant
- *Yes, it [choosing the GTI] matters! We looked at options, positive/negative, and together we came up with a decision. It is important as we go to the next stage that we 'own' the option chosen* IRL Health Service Planner

PLA: Sustained engagement

- *We also think the [PLA] system will work ... because people like these methods, they will go further on with this* NL Researcher

Impact on clinical settings

- Migrants and other stakeholders drove the implementation of their selected G TI forward with evidence of positive impact on practice (Teunissen et al., 2017)
- Health system level barriers identified

Involving migrants in health research to adapt primary care services

Problem & solutions in general practice
2002-2005
HRB

Developing guidelines
2009-2011
HRB and HSE

Implementation work in practice settings
2011-2015
EU FP7

Implementation work in health care system
2016-present
HSE

Summary

- Individual and community participation are embedded in, and required for, quality primary health care
- The rich tradition of participatory health research can guide the development of structures and spaces for partnerships, equal dialogue and meaningful engagement
- Participation is not a panacea
- Senior level and inter-sectoral dialogues must also take place to address system-level factors that need attention based on the 'voice' and recommendations arising from community participation



Key RESTORE project references

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- Lionis, C. et al., (2016) 'Engaging migrants and other stakeholders to improve communication in cross-cultural consultation in primary care: a theoretically informed participatory study', *BMJ open.*, 6(7),e010822
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- de Brún, T. et al (2017) 'Using Participatory Learning & Action (PLA) research techniques for inter-stakeholder dialogue in primary healthcare: an analysis of stakeholders' experiences'. *Research involvement and engagement*, 3(1), 28
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<http://www.ul.ie/gems/public-and-patient-involvement-ppi-research-unit>



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PPI and Participatory Health Research



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