How can user involvement add value to health research?

Expectations, opportunities and challenges

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NOPE, Bergen, 4.Nov 2021

Content

- History of PPI / User involvement
- What, who, why, when and how
- Some exemples
- Expectations
- Challenges
- Opportunities

“My Most Important Task” Eleanor Roosevelt

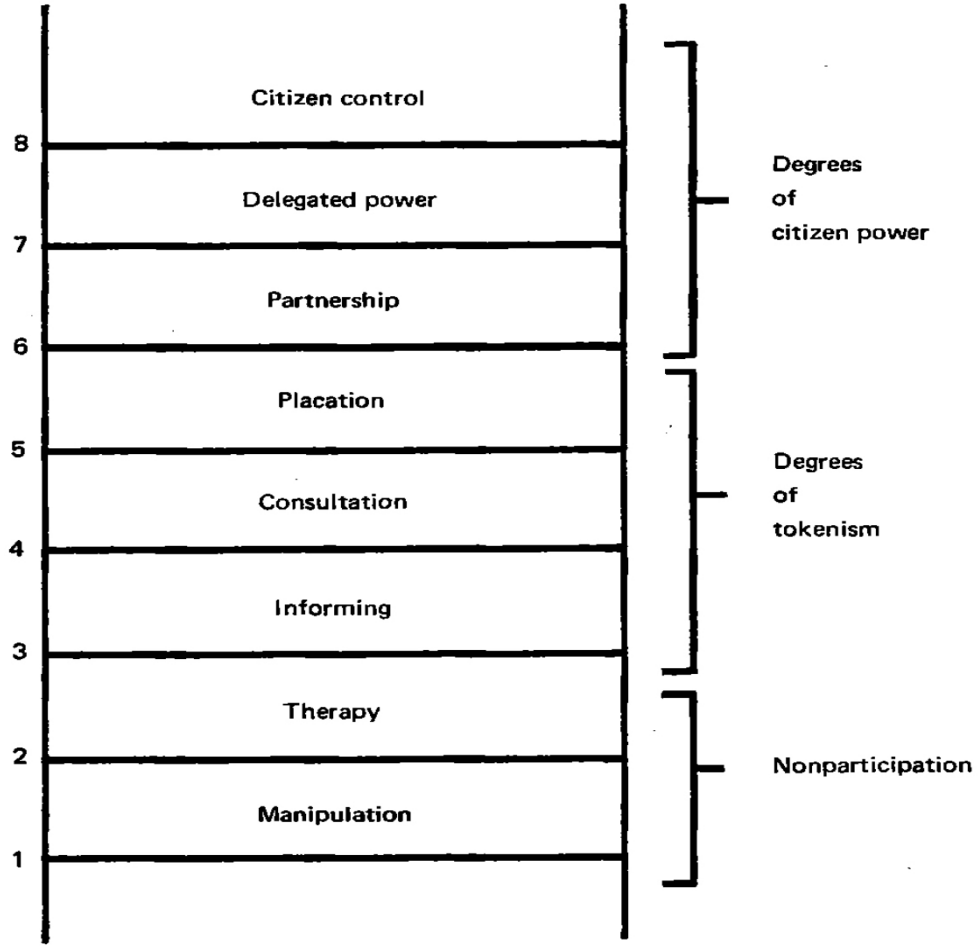
- The Universal Declaration of Human Rights adopted by the United Nations on December 10, 1948

1969 - Sherry Phyllis Arnstein, author of the journal article "A Ladder of Citizen Participation“.

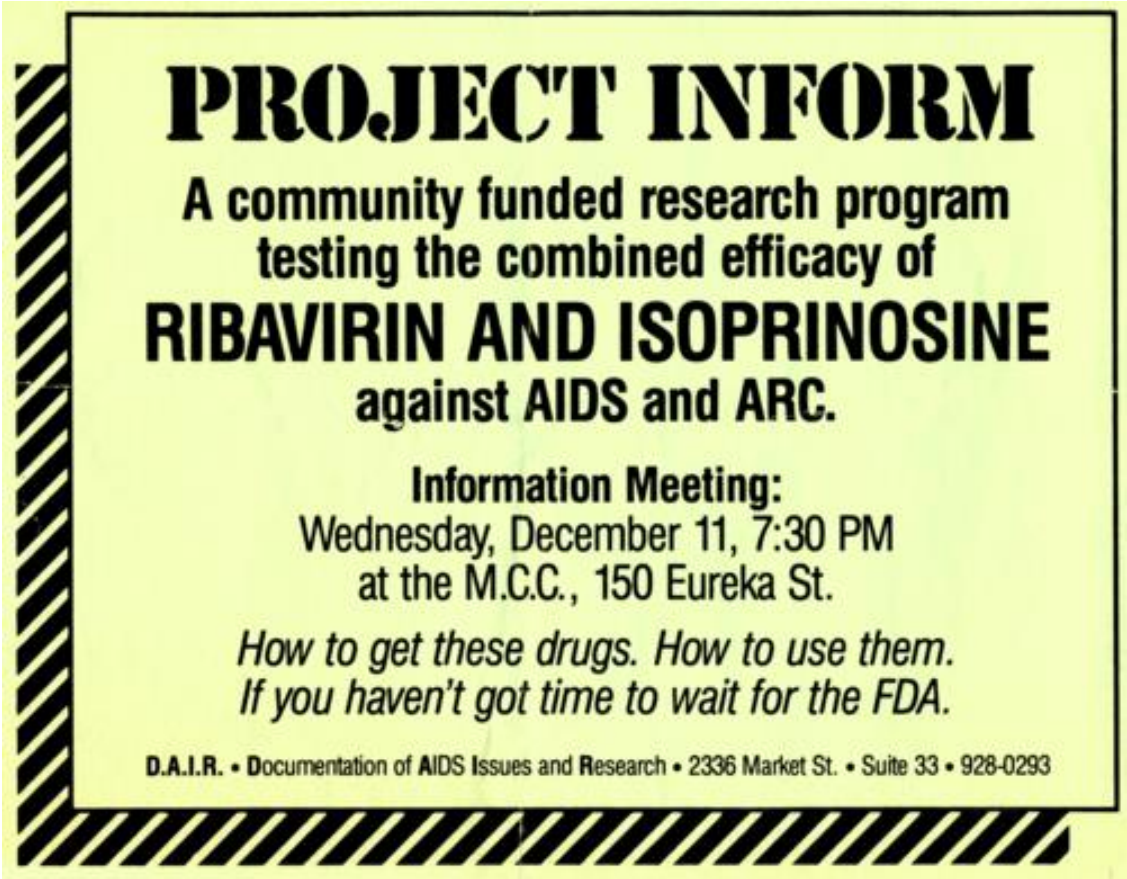
«It is all about empowerment !»

FIGURE 1 *French Student Poster. In English, I participate; you participate; he participates; we participate; you participate . . . **They profit.***

AIP JOURNAL JULY 1969



1980ties – HIV /AIDS activisme



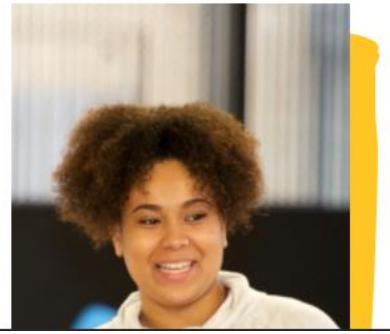
2010

involve

ABOUT OUR WORK RESOURCES GET INVOLVED SIGN UP

WE BELIEVE THAT PEOPLE SHOULD BE AT THE HEART OF DECISION-MAKING

LEARN MORE →



St.meld. nr. 25 (2005-2006)

Mestring, muligheter og mening

Helse- og omsorgsdepartementet

1 Innledning

Framtidas omsorgsutfordringer og hovedbrukerne av de kommunale helse- og omsorgstjenestene står i fokus i denne meldingen. De siste 20 årene har tjenestene gjennomgått flere store reformer som har berørt både eldreomsorgen og brukergrupper

Neste kapittel

Til dokumentets forside

Last ned dokument

Vis innholdsfortegnelse og søk

Enhance and augment userinvolvement in research and inovation

What is user engagement / patient and Public Involvement?

- Patient and Public Involvement (PPI) means actively working in partnership with patients and members of the public to plan, manage, design and carry out research.
- It is “Research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them”

Why?

- Human rights
- Democratic rights
- Ethical assessments
- Quality and efficiency
- Equalization of power - empowerment
- Legal perspective

KEYS:

- Partnership
- Consent and formel collaboration
- Tutorial
- Direct involvement and/or all relevant stakeholders

Who are the users (stakeholders)?

1. Patients/relatives with experience preferrably linked to a patient organisation for support

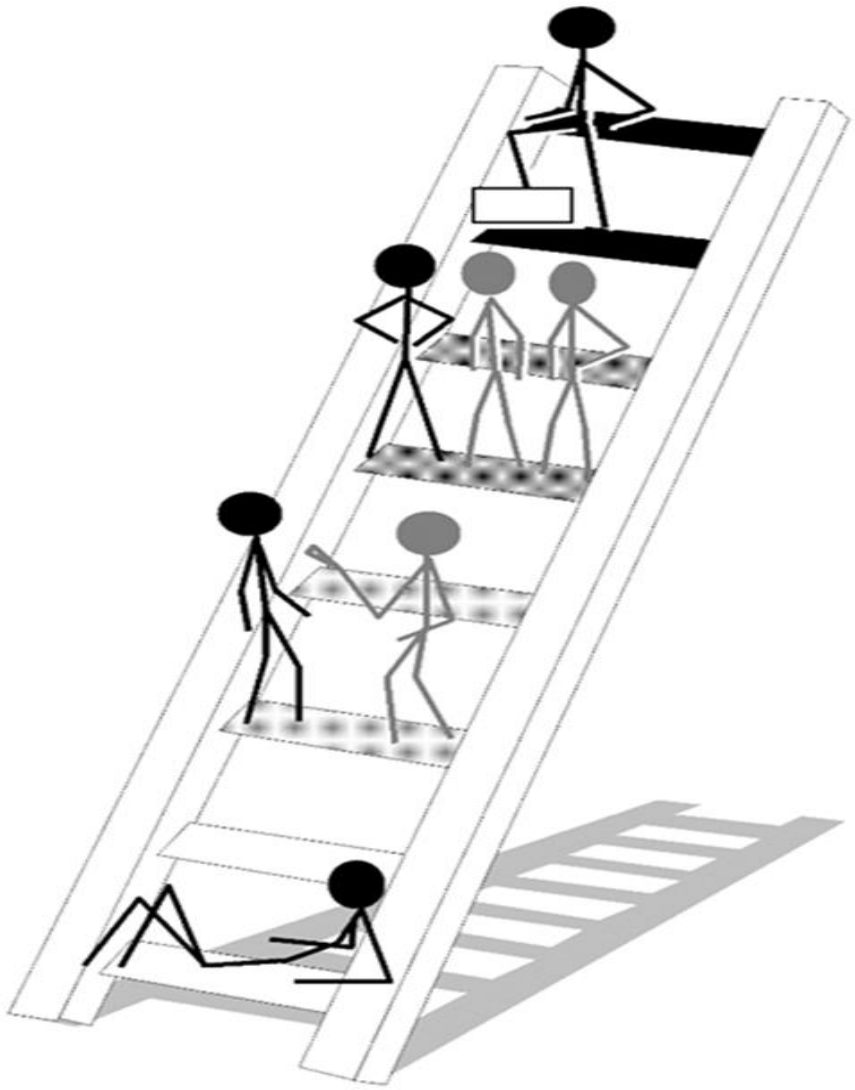
2. Staff from a patientorganisation

3. The general public?

4. Staff in the county / municipality gouvernance?

6. Medical staff?

How?



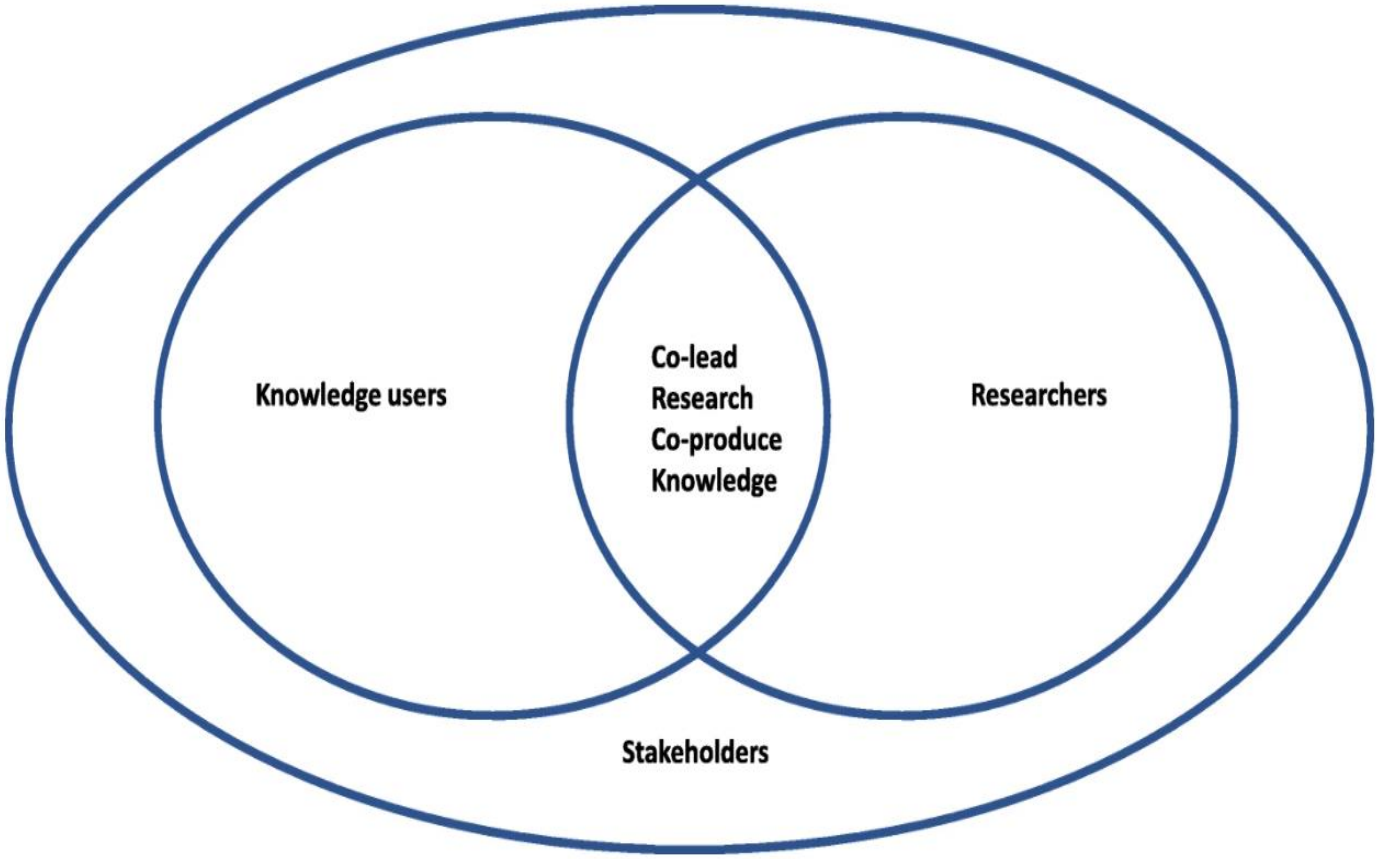
eular

fighting rheumatic & musculoskeletal diseases together

Nasjonalforeningen
for folkehelsen

Fig. 1

From: A review and synthesis of frameworks for engagement in health research to identify concepts of knowledge user engagement



Defining interests in co-production of knowledge

Ref. Jull, J.E., Davidson, L., Dungan, R. *et al.* A review and synthesis of frameworks for engagement in health research to identify concepts of knowledge user engagement. *BMC Med Res Methodol* **19,** 211 (2019).

Key Principles:

1. **Trust**
2. Relationship building
3. Identify shared priorities
4. Diversity in membership
5. Partnered activities
6. Transparency
7. Mutual respect and recognition

Priority Setting Partnerships

https://pubmed.ncbi.nlm.nih.gov/32606070/

Open Heart. 2020 Jun;7(1):e001258. doi: 10.1136/openhrt-2020-001258.

Research priorities in advanced heart failure: James Lind alliance priority setting partnership

Clare J Taylor [1], Alyson L Huntley [2], John Burden [3], Amy Gadoud [4], Toto Gronlund [5], Nicholas Robert Jones [6], Eleanor Wicks [7], Sara McKelvie [8], Kit Byatt [9], Richard Lehman [10], Anna King [11], Bev Mumford [12], Gene Feder [2], Jonathan Mant [13], Richard Hobbs [14], Rachel Johnson [15]

Affiliations + expand

PMID: 32606070 PMCID: PMC7328807 DOI: 10.1136/openhrt-2020-001258

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Abstract

Abstract

Objective: To determine research priorities in advanced heart failure (HF) for patients, carers and healthcare professionals.

Methods: Priority setting partnership using the systematic James Lind Alliance method for ranking and setting research priorities. An initial open survey of patients, carers and healthcare professionals

autisme_stakeholderdriven_ 2020.pdf

Check for updates

Mental Health Across the Lifespan

autism

Listening to the autistic voice: Mental health priorities to guide research and practice in autism from a stakeholder-driven project

Autism
2020, Vol. 24(4) 822–833
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DOI: 10.1177/1362361320908410
journals.sagepub.com/home/aut
SAGE

Teal W Benevides[1], Stephen M Shore[2], Kate Palmer[3], Patricia Duncan[3], Alex Plank[3], May-Lynn Andresen[4], Reid Caplan[3], Barb Cook[5], Dena Gassner[2], Becca Lory Hector[3], Lisa Morgan[3], Lindsey Nebeker[3], Yenn Purkis[3], Brigid Rankowski[6], Karl Wittig[3] and Steven S Coughlin[1]

https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-01570-3

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BMC Geriatrics

Research article | Open Access | Published: 14 May 2020

It takes two to tango: carers' reflections on their participation and the participation of people with dementia in the James Lind Alliance process

Agnete Nygaard, Liv Halvorsrud, Asta Bye & Astrid Bergland

BMC Geriatrics **20**, Article number: 175 (2020) | Cite this article

815 Accesses | **1** Altmetric | Metrics

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Section

Health services research

Sections References

Abstract

Background

Methods

Results

Discussion

Conclusion

Availability of data and materials

Abstract

Background

Worldwide, patient and public involvement (PPI) in health research has grown steadily in

https://www.comorment.uio.no

Search

CoMorMent

Investigating comorbid mental ill-health
& cardiovascular disease

Home | Our research | News and events | Publications | Press and Outreach | About us

Using a 'big data' approach, we investigate how & why mental ill-health interacts with cardiovascular disease.

Includes a stakeholderboard with patients, patientorganiation representatives DNV, more..

Norsk register for personer som utredes for kognitive symptomer i spesialisthelsetjenesten - NorKog

SE RESULTATER

Norsk register for personer som utredes for kognitive symptomer i spesialisthelsetjenesten (NorKog) er det nasjonale kvalitetsregisteret for utredning av kognitive symptomer og/eller demens.

UK Longitudinal Linkage Collaboration

Linking Data for Future Research Discoveries

The UK Longitudinal Linkage Collaboration (UK LLC) has been set up to bring together information from longitudinal study volunteers with their routine records. This is being done in a secure way to help researchers work to improve health and wellbeing throughout and beyond the COVID-19 pandemic.

A new collaboration for public benefit

including improving the way that research is conducted, designed, communicated and shared.

UK Longitudinal Linkage Collaboration

HOME ABOUT US RESEARCHERS PATIENT & PUBLIC INVOLVEMENT

One of the UK LLC's values is to operate in a transparent way to build trust with the public and longitudinal research volunteers participating through the collaborating studies.

This will happen through a variety of involvement methods:

1

The UK LLC Data Access Review Panel will include study participants and/or members of the public who, along with UK LLC staff and study representatives, will be involved in considering applications from researchers to use the data held on the secure research

2

The UK LLC Advisory Group is a core group of study participants and/or members of the public who will be recruited from April 2021. This group will meet regularly to be involved in the creation and design of UK LLC operational and communications aspects of

3

The UK LLC Involvement Network is a larger network of lay members of the public who will be recruited from April 2021. This network will be able to support the work of the UK LLC on an ad-hoc basis.

Expectations from the reseachers

- Be an equal partner
- Brings in experience and user knowledge that can not be obtained elsewhere
- Perform the work carefully and seriously (conscientiously)
- Be prepared as other partners
- Participates actively and constructively in the dialogue
- Ask when there is something you are wondering about
- Must balance the personal and the private
- Avoid “fixation / fads"
- Be able to communicate the results to / in their groups

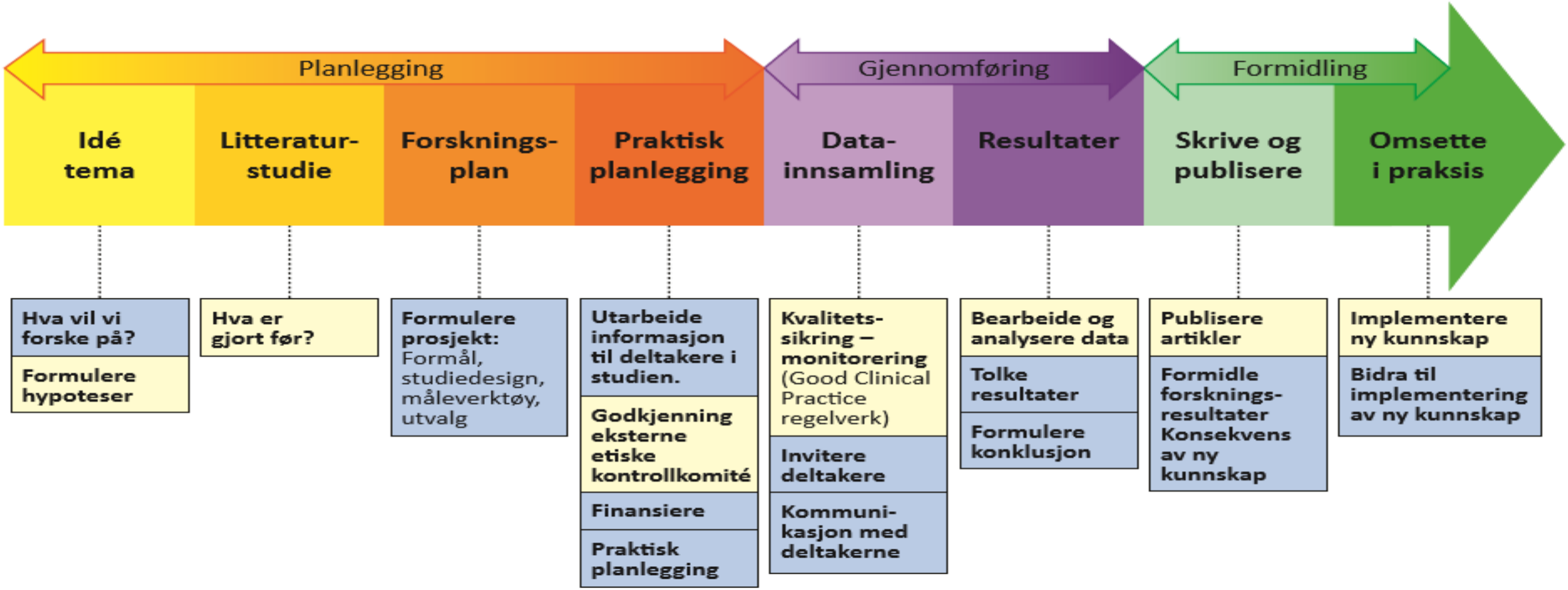
Expectations from the users

- Be included as an equal partner
- Never alone -provide a peer
- Use a language that everybody understands
- Be aware of the users' health competence / incompetence
- Must receive training, use tools that are suitable for the purpose , mayby work this out together?
- Wants to contribute where it can lead to benefit (relevance, quality, dissimination and implementation)
- Wants and expects to receive an update on what is happening (newletter?)
- Wants to contribute to the dissemination of the results
- Have to be included in the total project budget

What might hamper user participation?

- That the participation is not perceived as “real” by the user - "hostage" and not partner
- May feel threatening by lay people without health expertise.
- Lack of method and competence about user participation among researchers and users.
- Culture, values and attitudes
- Do not speak the same "tribal" language
- Lack of time
- Lack of finances and resources
- Little support from the project management
- Little support and follow-up from user organizations

Brukermedvirkning i forskning



Forskningspila for brukermedvirkning er ment som hjelpemiddel i planlegging og gjennomføring av brukermedvirkning i forskning.
Utarbeidet av EUPATI og bearbeidet til norsk av FORMI, OUS.

Høyt krav til medisinsk/forskerkompetanse Godt egnet til brukermedvirkning

How it might work

Consultation: understanding the causes of obesity in people with mental illness with co-produced methods

Explaining where the data comes from and how the results are made. Giving people trust in the methods

Research finding: the link between mental ill-health and cardiovascular disease is stronger for obese people, regardless of genetics

Dissemination: telling people what we found in accessible terms that they can make sense of

Implementation: translating the findings into recommendations for people and their doctors

How to get started

- **Make a plan for user involvement**
- What is the purpose of the participation?
- What level?
- In what way?
- How to get user participation within this project?
- Methods?
- What tools are useful in my setting?
- Who will contribute when and to what?
- Co-researcher?
- What is the significance of user participation in this work?
- Benefits?
- Evaluation?
- How is research affected?
- Documentation?
- Own article?

Take home message

- **Take user engagement seriously**
  - Read the literature, learn the methods, “start low and move slow”
  - Commit resources
  - Understand the process and its (your) limitations
  - Seek out expertise

- **Take science communication seriously**

- **Invest in relationships**
  - Be honest
  - Be transparent
  - Build trust
  - Be a buddy