Patient involvement in the IMI APPROACH project
Invaluable insights and key ingredients

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Patient engagement in APPROACH

- 2 consortium partners (Arthritis Research UK & Dutch Arthritis Foundation)
- Very active Patient Council, supported by Lygature

Jane Taylor (UK), Maureen Grossmann (UK), Sjouke Dekker (NL), Jon Skandsen (NO), Kaoutar Douieb (SP), Diny Jurg (NL)
Why? Because research benefits

- Protocol
- Communication
- Patient-doctor interactions
- Evaluation

IMPROVED SCIENCE & RETENTION
Key ingredients for successful patient involvement

Before kick-off:
- Involve patients in shaping & reviewing of the bid
- Allocate appropriate funding

After kick-off:
- Aim for diversity
- Provide an organizational structure
- Define expectations
- Maintain ongoing interactions & ensure informal contact
- Think about accessibility: physical, economic, linguistic, psychological
The bigger picture

Changing conversations

Normalizing patient-researcher relationships

Patient empowerment

Ethical imperative