



Patient Led Research Hub

Co-Producing research with patient partners

Dr Rona Smith

Senior Research Associate, University of Cambridge
Honorary Consultant in Nephrology and Vasculitis

- Public and patient involvement in research
- Patient led research hub (PLRH)
- Case studies of co-production of research by PLRH

What do we mean by Patient and Public Involvement (PPI)?

The 'researchers'



What do we mean by Patient and Public Involvement (PPI)?

The 'researchers'



The 'researched'



What do we mean by Patient and Public Involvement (PPI)?

The 'researchers'



The 'research team'



The 'researched'

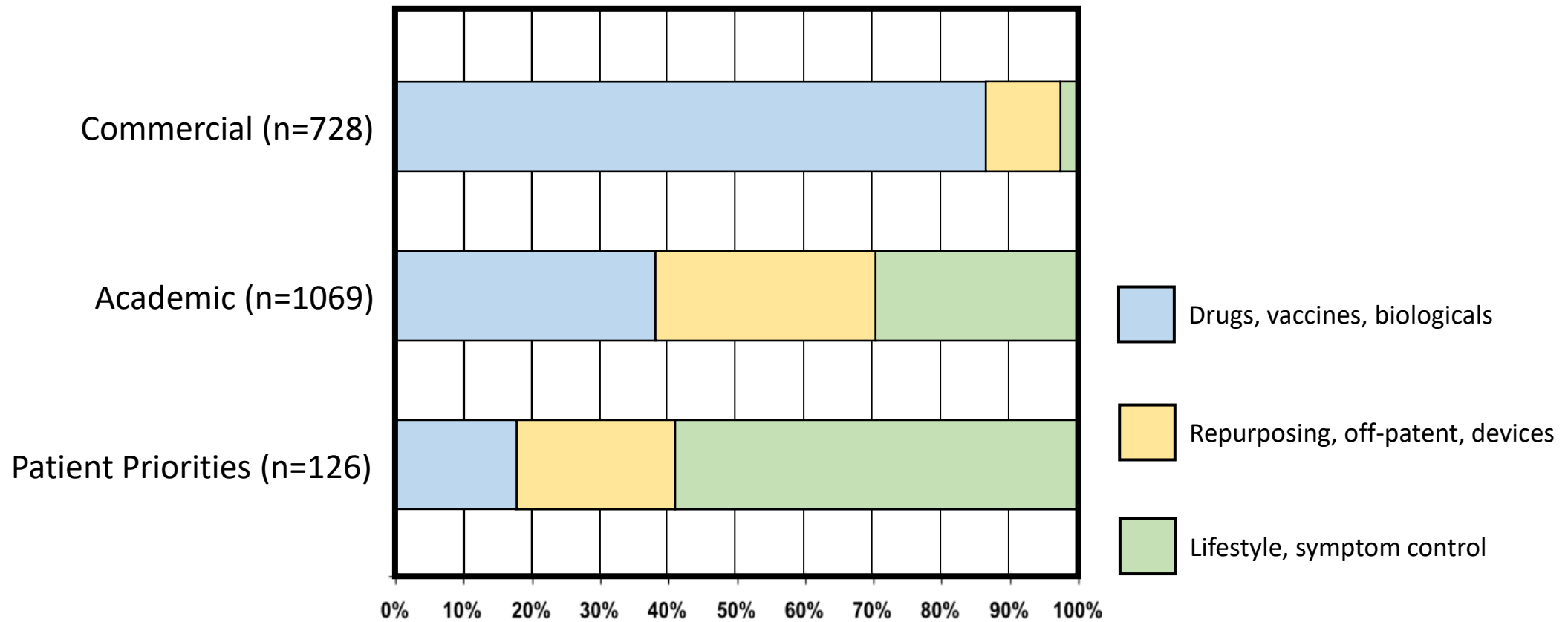


Involvement puts members of the public on the research team

Why perform PPI in research?

- Improves the quality and relevance of research.
- Uses methodologies that participants are more likely to engage with, can
- Reduce research waste

Mismatch of expectations



What does good PPI look like in a trial?

- ✓ Involves a variety of relevant voices
- ✓ Starts early and encompasses the full research process
- ✓ Actively pursues inclusivity & diversity
- ✓ Uses methods appropriate to audience and research
- ✓ Focuses on communication and clarification
- ✓ Acknowledges contributions and provides feedback
- ✓ Reflects on outcomes

PPI throughout the trial process

Design

- Refine research question
- Identify important outcomes
- Protocol feasibility and acceptability
- Recruitment strategies
- Review patient-facing documents

PPI throughout the trial process

Design

- Refine research question
- Identify important outcomes
- Protocol feasibility and acceptability
- Recruitment strategies
- Review patient-facing documents

Delivery

- Committee representation
- Recruitment ambassadors
- Data/results interpretation

PPI throughout the trial process



- Refine research question
- Identify important outcomes
- Protocol feasibility and acceptability
- Recruitment strategies
- Review patient-facing documents

- Committee representation
- Recruitment ambassadors
- Data/results interpretation

- Audience mapping
- Information placement
- Accessible language
- Message identification
- Co-authorship
- Dissemination plans

Types of PPI

- **Consultation**
- **Collaboration**
- **Co-production**

Types of PPI

- **Consultation**

- Asking people for their views
- One off meetings - patient panel

- **Collaboration**

- **Co-production**

Types of PPI

- **Consultation**

- Asking people for their views
- One off meetings - patient panel

- **Collaboration**

- active, on-going partnership with members of the public in the research process
- members of a steering committee for a research project
- design, undertake and/or disseminate the results of a research project

- **Co-production**

Types of PPI

- **Consultation**

- Asking people for their views
- One off meetings - patient panel

- **Collaboration**

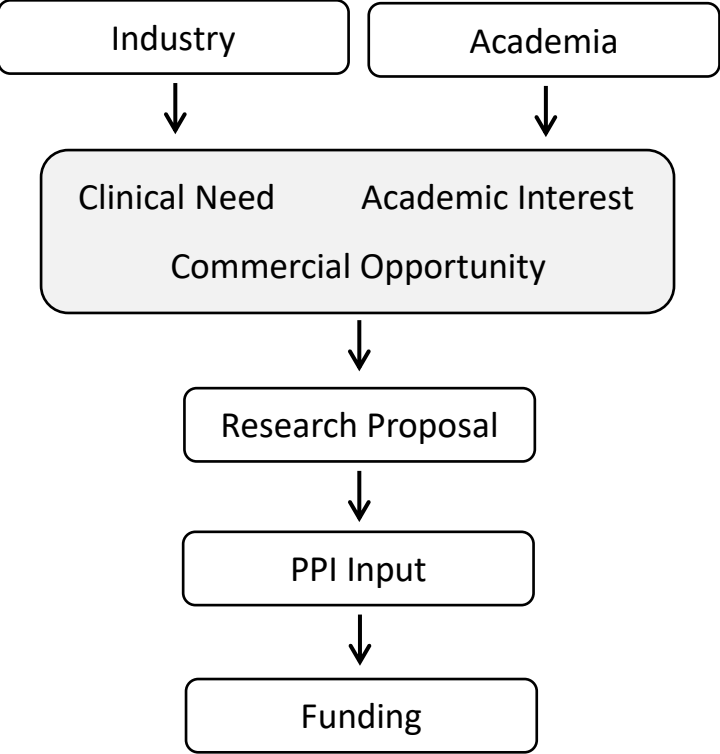
- active, on-going partnership with members of the public in the research process
- members of a steering committee for a research project
- design, undertake and/or disseminate the results of a research project

- **Co-production**

- Researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge

Types of PPI

Traditional PPI



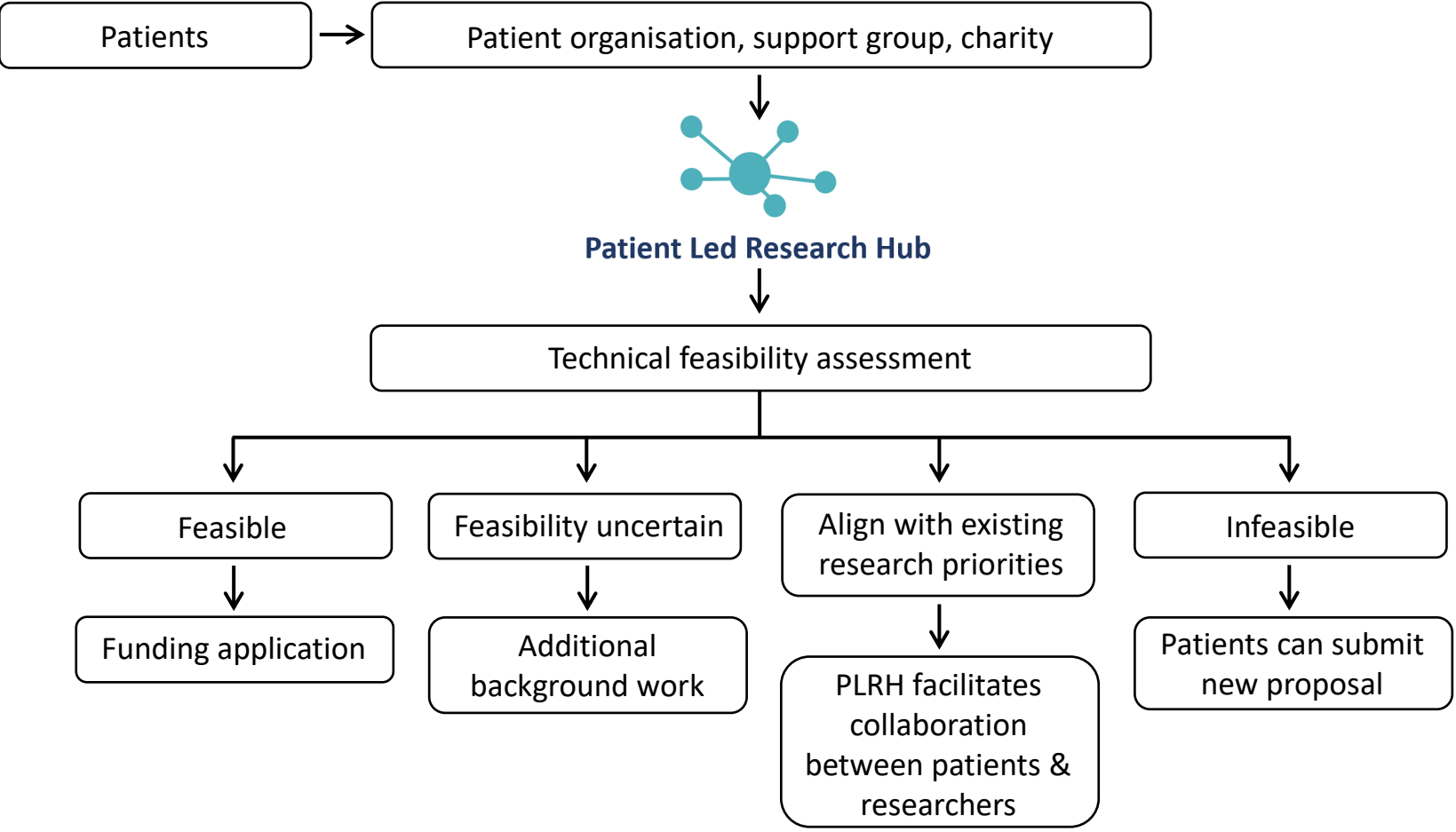


Patient Led Research Hub

Supporting patient-led research
Co-producing clinical trials with patient organisations

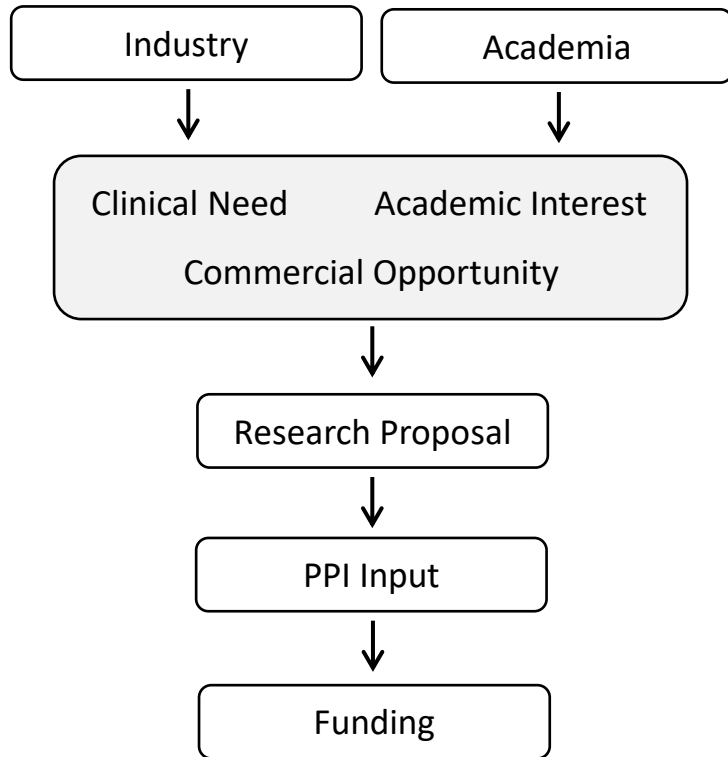
Types of PPI

PLRH Approach

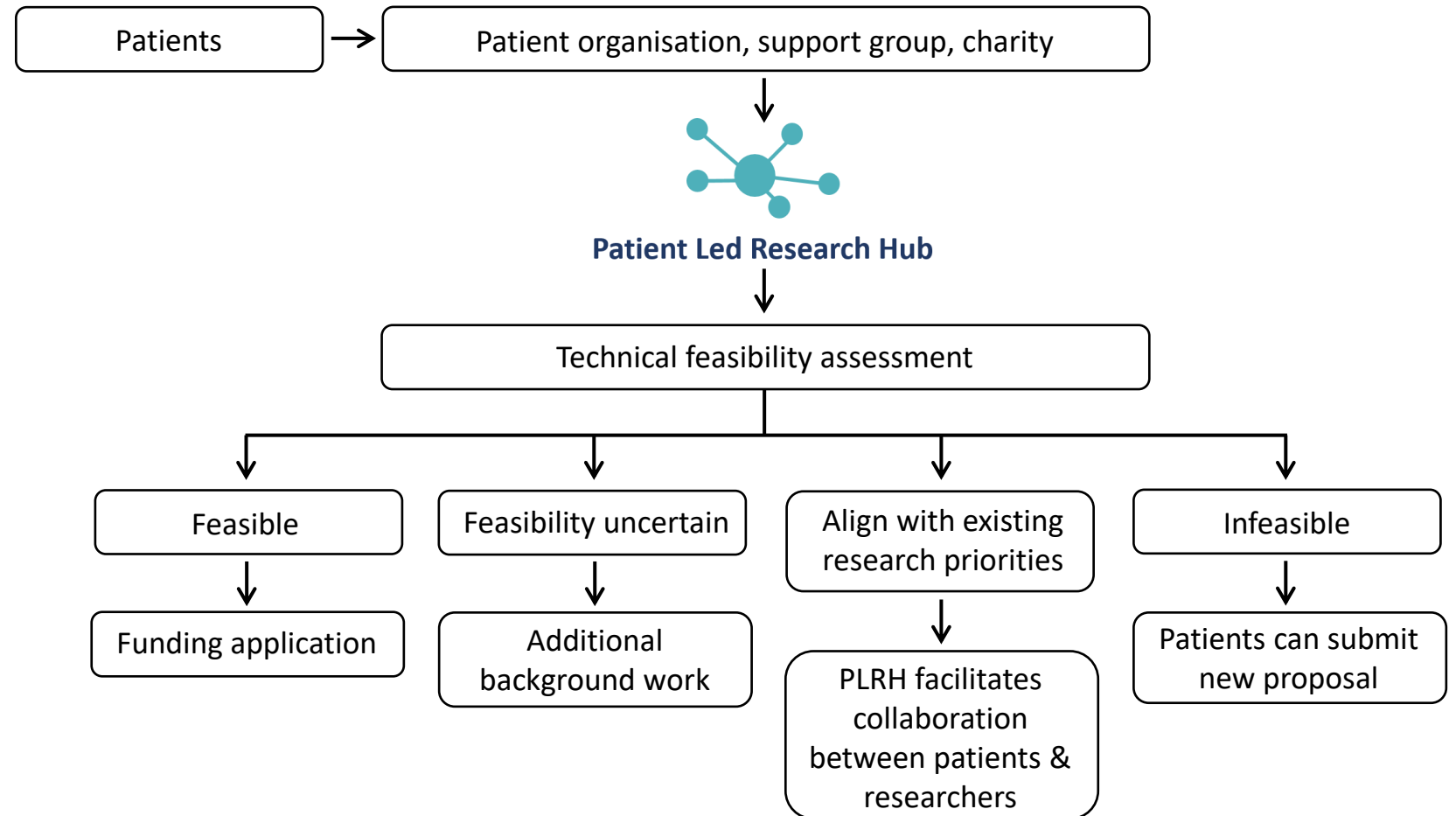


Types of PPI

Traditional PPI



PLRH Approach



Establishing the PLRH

- Support and co-produce research ideas proposed by patient organisations
- Free from research agenda: any original research idea on any healthcare topic
- Patient organisation maintains active role throughout project: multidisciplinary team with patients, researchers, clinicians
- Focus on patient priorities benefits funding applications
- Partnership builds trust with patient population: increased recruitment & adherence, wider dissemination network

Establishing the PLRH

- Support and co-produce research ideas proposed by patient organisations
 - Free from research agenda: any original research idea on any healthcare topic
 - Patient organisation maintains active role throughout project: multidisciplinary team with patients, researchers, clinicians
 - Focus on patient priorities benefits funding applications
 - Partnership builds trust with patient population: increased recruitment & adherence, wider dissemination network
-
- Core funding from Cambridge Biomedical Research Centre
 - Nested within the Cambridge Clinical Trials Unit
 - Supported by the University of Cambridge School for Clinical Medicine
 - Governed by the Cambridge University Hospitals PPI Research Oversight Group



**55 research ideas
from 24 patient organisations
& 24 individuals**



44 health conditions



**23 feasible projects
0 pending review**



Patient Led Research Hub

ALL PLRH projects
updated 03 October 2022



55 research ideas
from **24 patient organisations**
& **24 individuals**



44 health conditions



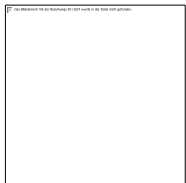
23 feasible projects
0 pending review



Patient Led Research Hub



3 referred to specialist research centres
2 linked to ongoing studies
5 deferred at proposer request



13 co-produced proposals



3 projects in development

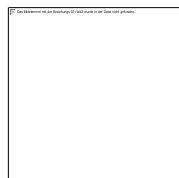


6 active, funded projects
3 completed projects

ALL PLRH projects
updated 03 October 2022



Patient Led Research Hub



55 research ideas
from **24 patient organisations**
& **24 individuals**



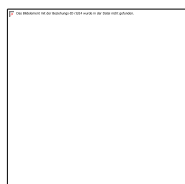
44 health conditions



23 feasible projects
0 pending review



3 referred to specialist research centres
2 linked to ongoing studies
5 deferred at proposer request



13 co-produced proposals



3 projects in development



6 active, funded projects
3 completed projects



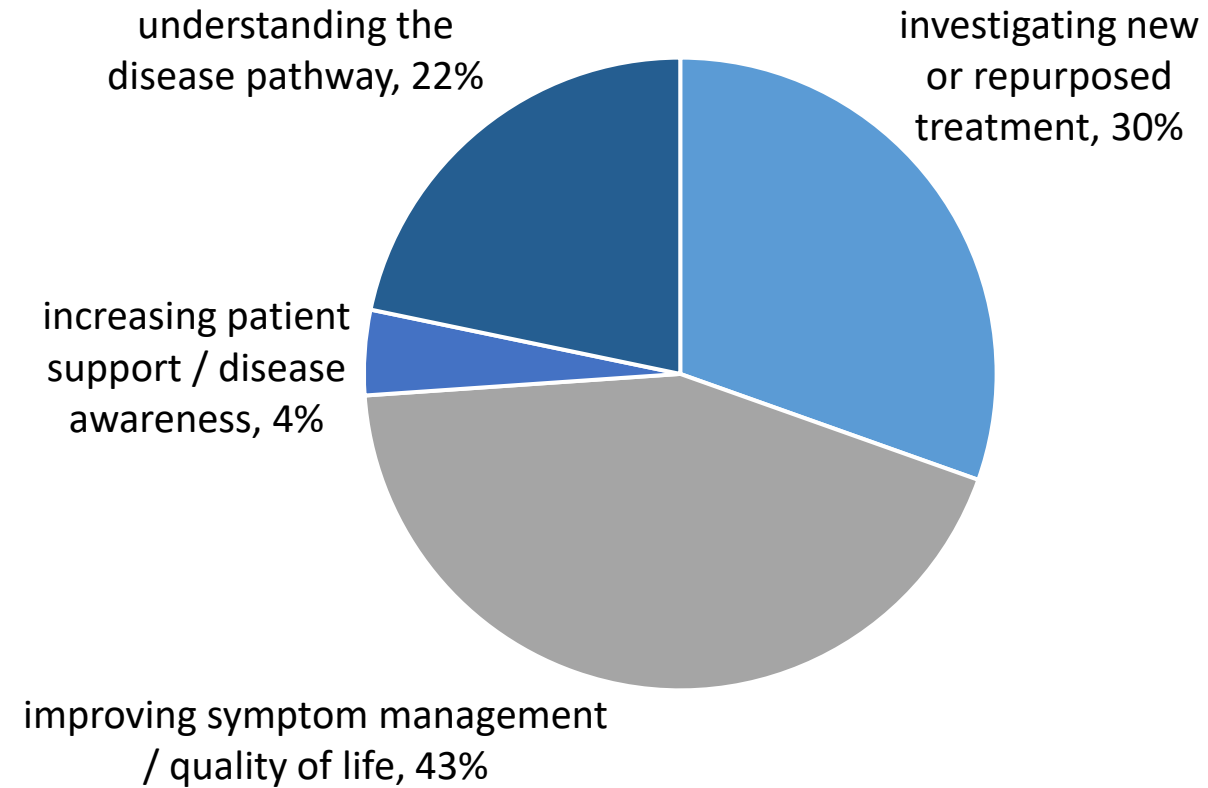
32 projects not feasible

- 9 without support from a UK patient organisation
- 7 did not respond to follow-up
- 6 proposals without new research component (e.g. treatment already available or awareness campaign)
- 5 from organisations already supported by experienced research teams
- 3 unable to commit to project
- 2 direct requests for funding

ALL PLRH projects
updated 03 October 2022

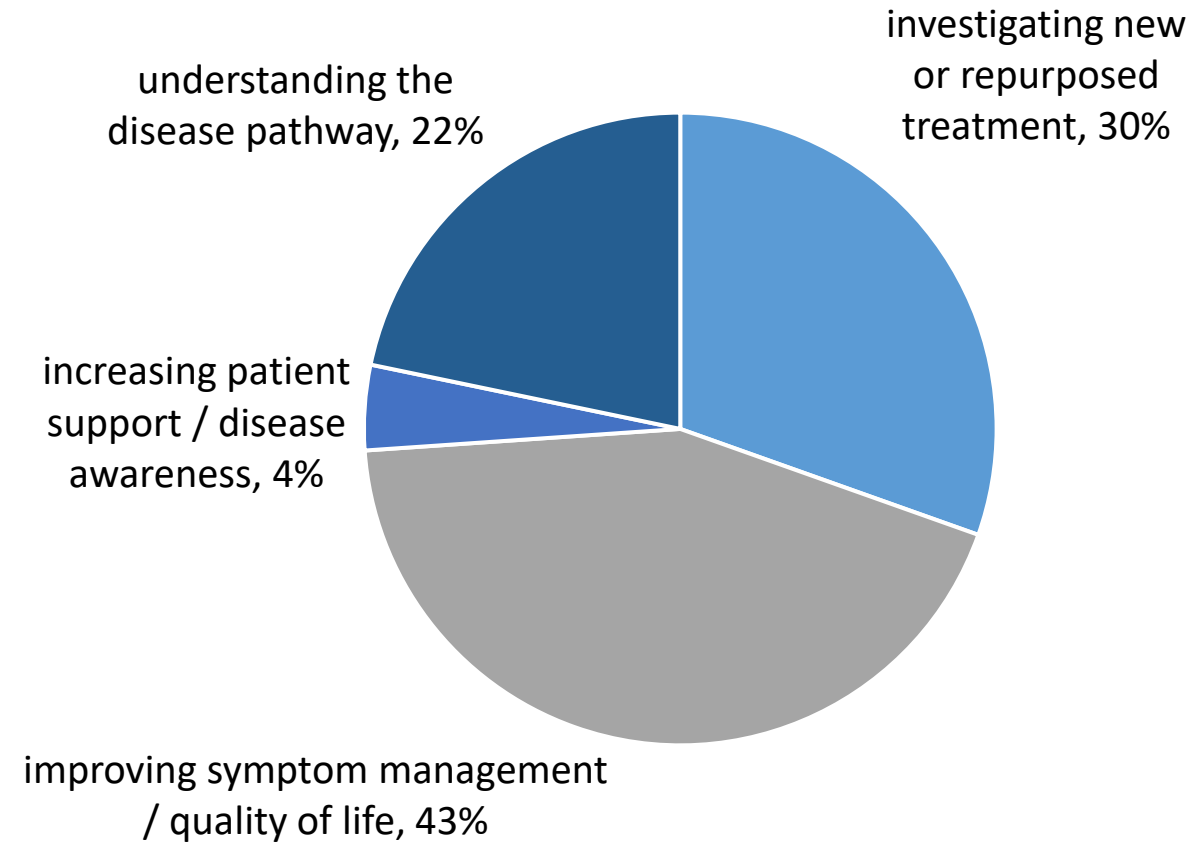
Feasible proposals

Research Priority

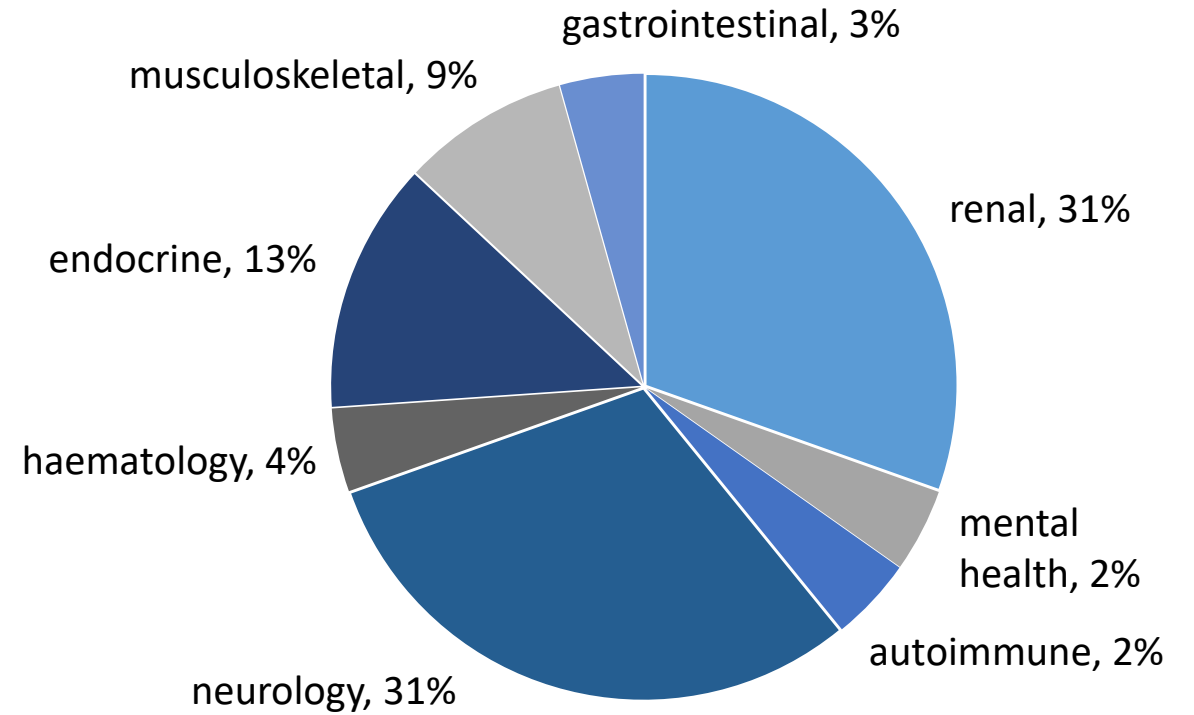


Feasible proposals

Research Priority



Research Topic



Key Challenges

- Managing patient expectation
- Efficiently engaging researchers & clinicians
- Sourcing seed funding to support feasibility work
- Appropriately involving patients throughout project
- Building a PLRH network
- Increasing core capacity

Supporting inclusive involvement

- Inclusivity takes planning and conscious effort
- ‘One-size-fits-all’ thinking results in contributors of that ‘size’
- Offer a variety of ways to get involved
- Think broadly about the groups that are underheard in your research
- Direct invitations can help – use your networks and invite people personally
- Make use of existing community groups – and go to them first
- Enter others’ ‘comfort & convenience’ zones
- Ask about needs before and after first meetings
- Plan for end of study



Enabling success

Resources

- Staff
- Financial
 - Reimbursement
 - Honoraria
 - Accessibility
- Skills & training

Attributes

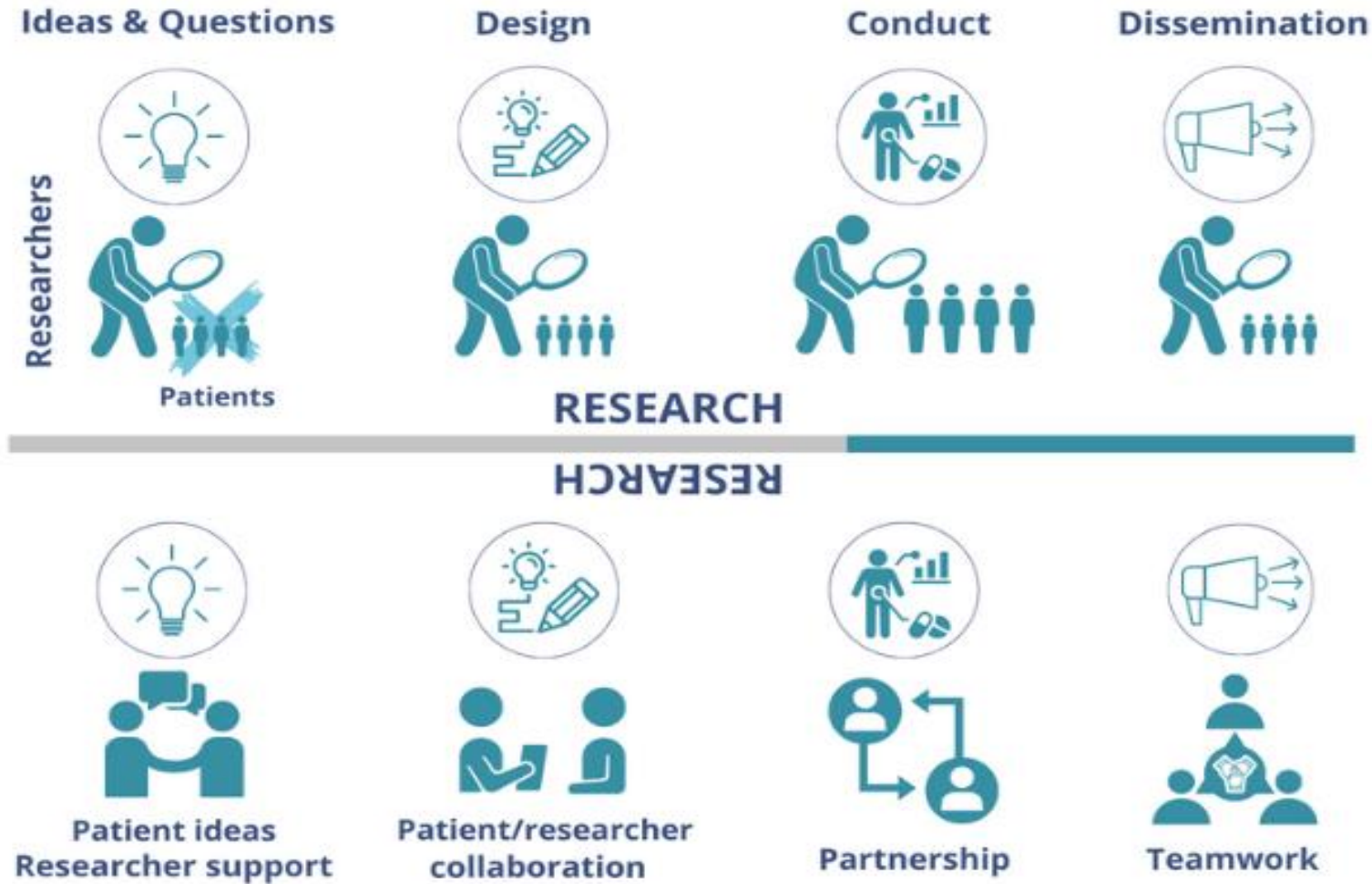
- Commitment
- Leadership
- Consistency



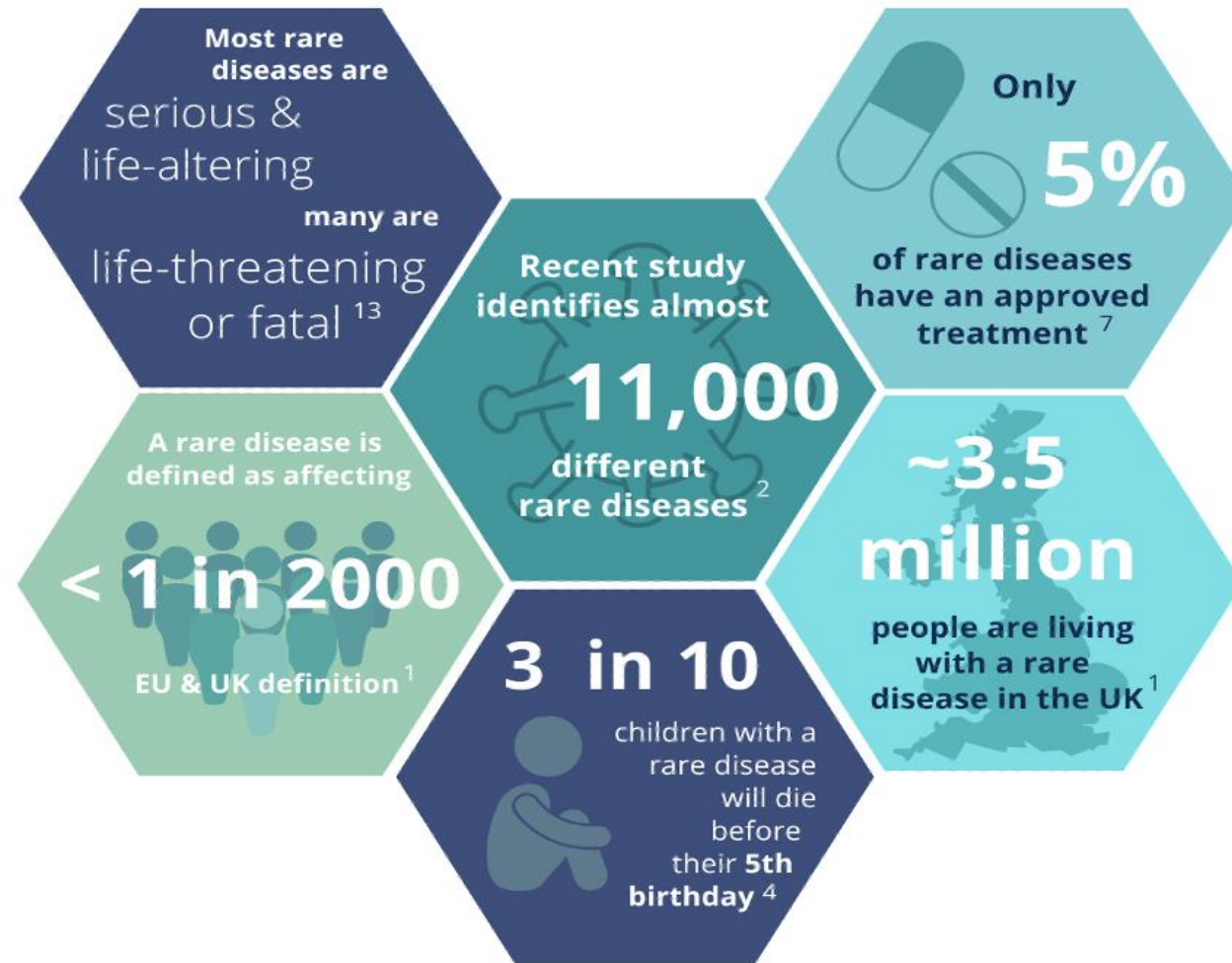
A new way of working.....



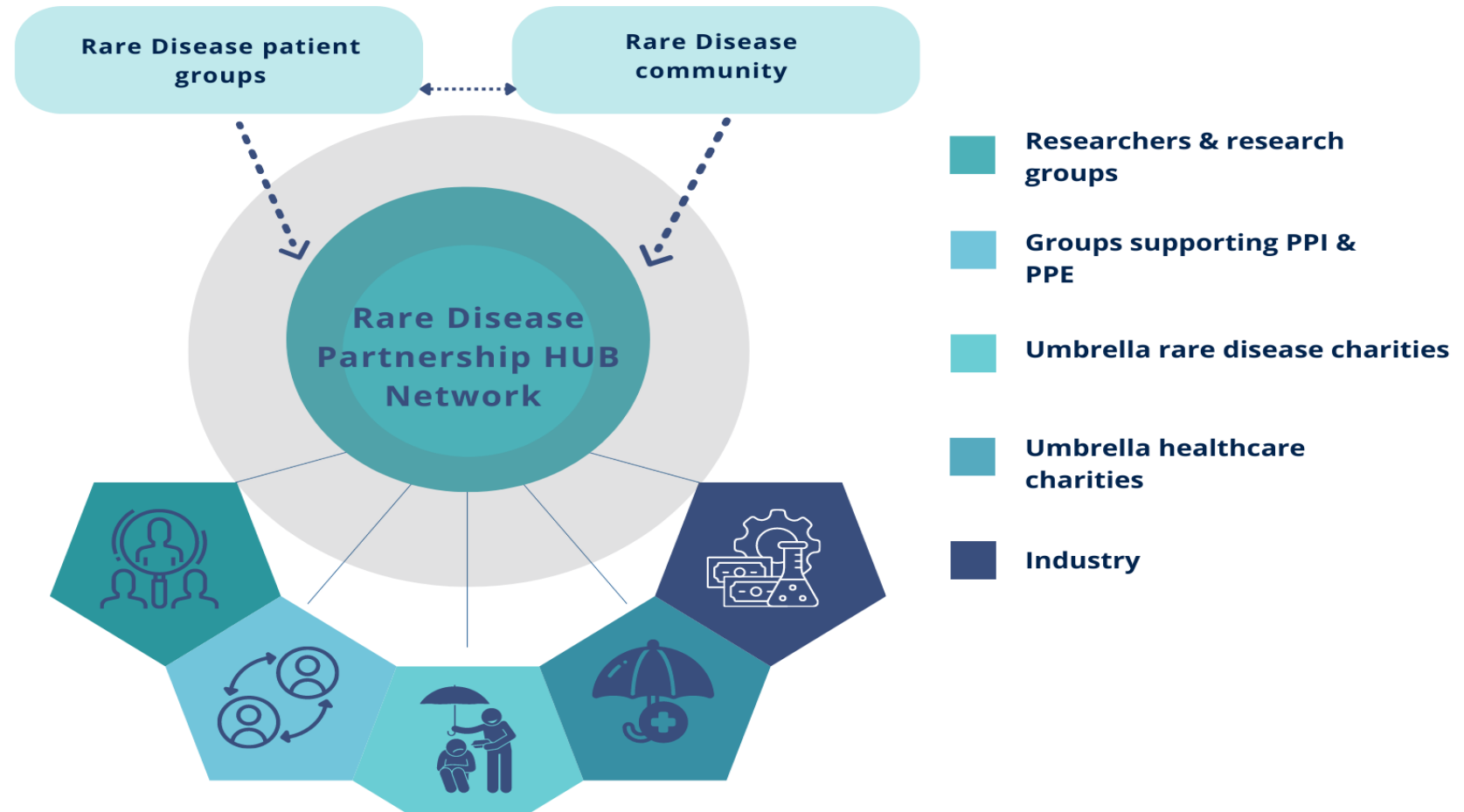
A new way of working.....



Rare disease focus



Rare disease focus



Case studies



Case studies



Case studies



Case studies



"No matter how complicated the research, or how brilliant the researcher, patients and the public always offer unique, invaluable insights. Their advice when designing, implementing and evaluating research invariably makes studies more effective, more credible and often more cost efficient as well"

Professor Dame Sally Davies (Chief Medical Officer England, Foreword in Staley report, 2009)



Patient Led Research Hub

info@plrh.org

[@PLRH_Cambridge](https://twitter.com/PLRH_Cambridge) • plrh.org