Rare Disease Research Network

Building a rare disease research network for a patient-led approach

Patient Led Research Hub

camRARE
Cambridge Rare Disease Network

Turning **Research** on its Head

The Rare Disease Research Network is a partnership project between CamRARE and Patient Led Research Hub, funded by the National Institute for Health and Social Care Research (NIHR) and sponsored by Cambridge University Hospitals NHS Foundation Trust.

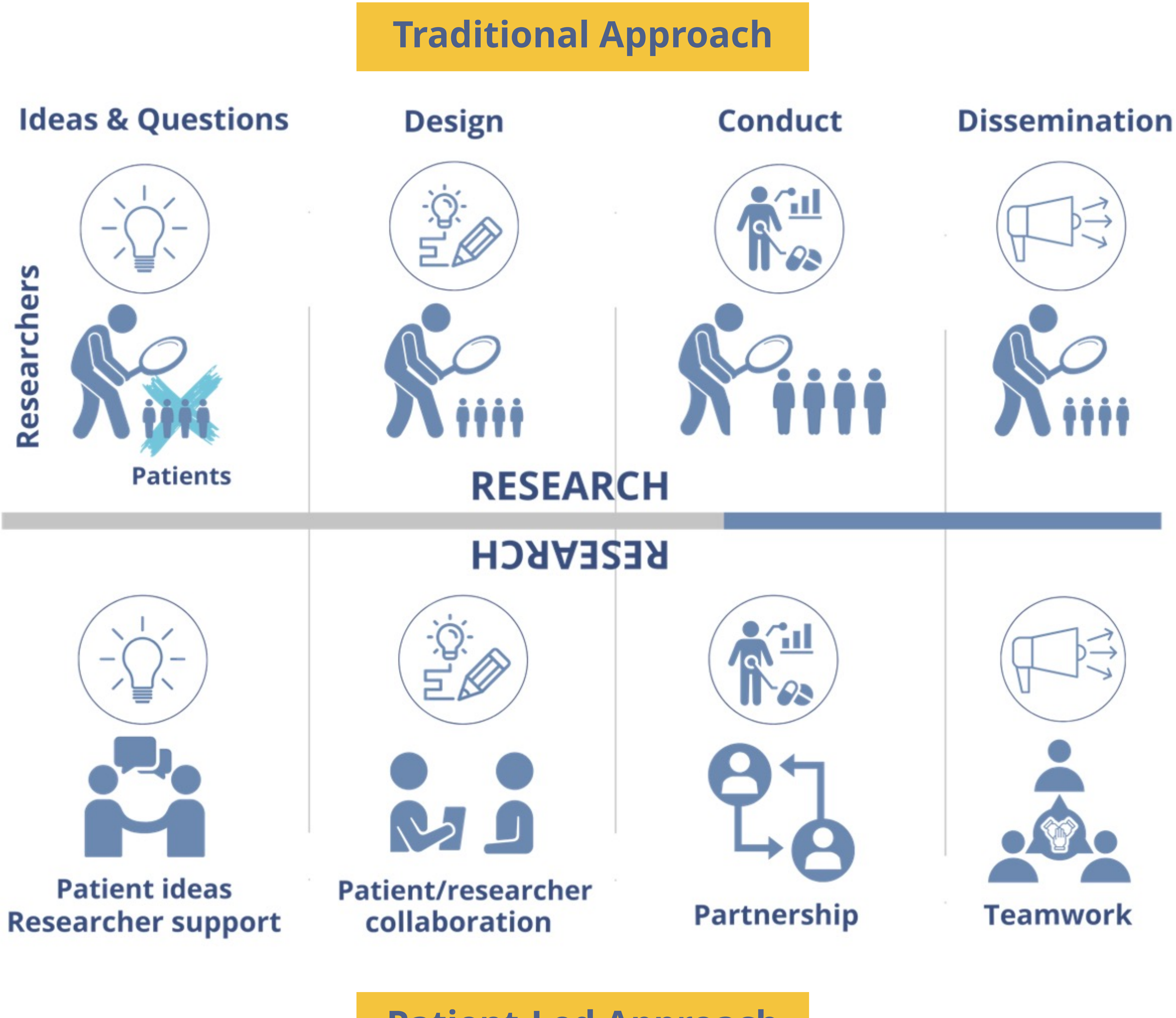
The project aims to support the rare disease community in building an online network of partnerships and resources to facilitate new patient-centred research opportunities. We hope it will be co-produced by members of the rare community, with wider engagement supported through additional outreach.

“ The concept of this new network would allow for more rare diseases (and the patient groups supporting their communities) to be seen and be heard in the research space, creating a more equitable field for all. This model turns the current approach to identifying new research opportunities on its head. The potential to open up collaboration between researchers, biopharma industry and patient groups is huge...who knows where this may lead? "

Allison Watson – CEO of Ring20 Research and Support CIO

WHY?

Is the current model of research working for patients? Are research questions which are important to patients, families and caregivers reflected in research conducted in academia, healthcare and industry? Are patient ideas, insights and expertise included in research from the earliest stages and throughout the process of research? We think not, and hope that the development of a community-led rare disease research network will help turn research on its head.



Traditional Approach

Ideas & Questions

Design

Conduct

Dissemination

Researchers

Patients

RESEARCH

RESEARCH

Patient ideas
Researcher support

Patient/researcher
collaboration

Partnership

Teamwork

Patient-Led Approach

Fig.1

RDRN TURNING RESEARCH ON ITS HEAD

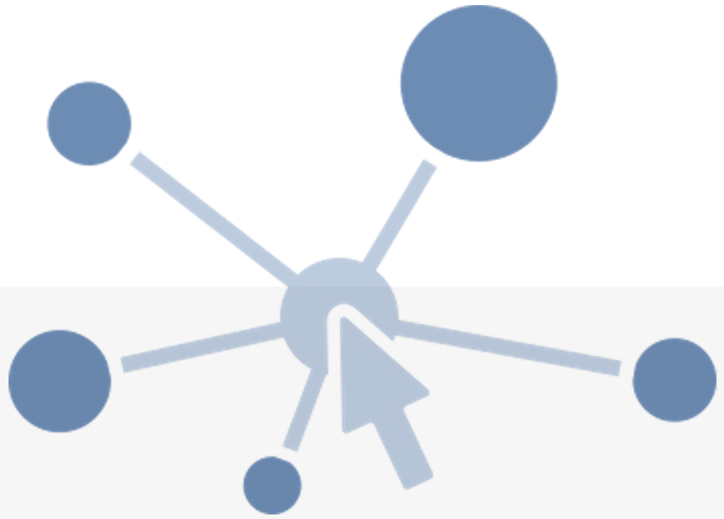
AIMS

- To build a network of people and organisations interested in rare disease research (see fig.2)
- To create a place online for this network to meet
- To create and share resources to help patients be involved in research
- To give patients a place to showcase their research ideas and connect with potential partners
- To create and widely share a report of the findings of this project

OBJECTIVES

- Identify partners and create focus groups
- Run workshops and community outreach to develop an online platform
- Design the platform's look, content and usability; run a pilot to get feedback and make changes
- Co-produce patient centered research resources
- Run workshops and community outreach to improve future research design
- Recruit research partners to the network and platform
- Explore models of long-term sustainability

WHY AN ONLINE NETWORK?



Interactivity

Visibility; a place to showcase ideas, unmet needs and a call to action; optimal opportunities to connect; a central base to gather and signpost to research resources – these are all essential to a patient group's success in research. An online platform offers consistency, adaptability and inclusivity.

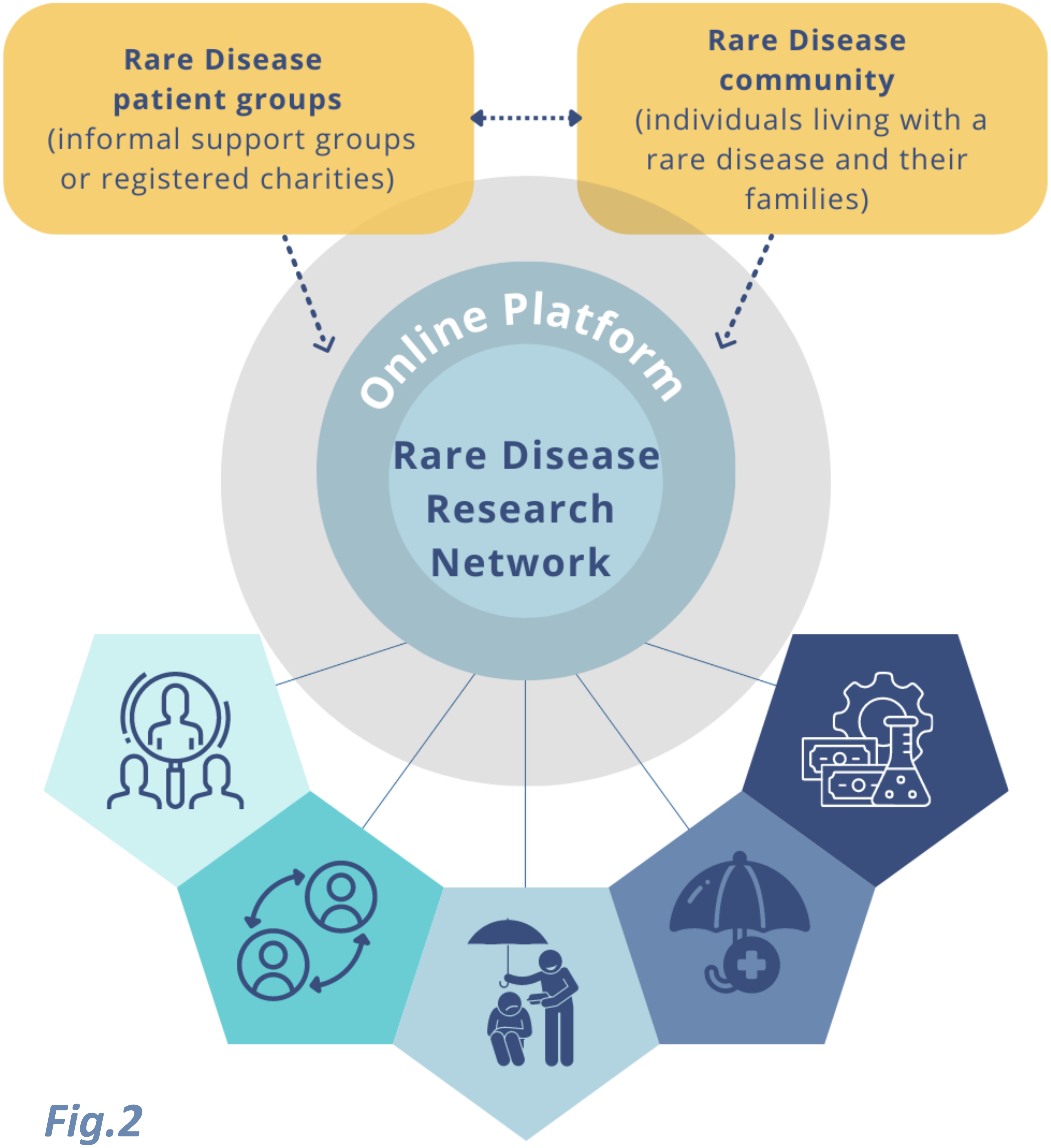
Accessibility

An online platform lends itself to being adapted for a broad range of accessibility preferences to suit those with sensory impairments and who are neurodiverse. It also allows for translation to other languages. We want all our stakeholders to be able to engage to their maximum ability, wherever they are.

Growth

This platform will grow, evolve and develop over time as new members join, share their ideas and collaborations form. It is the beginning of a journey towards a new way of instigating, conducting and collaborating on patient-centered rare disease research.

WHO WILL THE NETWORK INCLUDE?



Rare Disease patient groups
(informal support groups or registered charities)

Rare Disease community
(individuals living with a rare disease and their families)

- ■ **Researchers & research groups** interested in rare diseases
- ■ **Groups supporting** patient involvement & engagement in healthcare research
- ■ **Umbrella rare disease charities** (supporting the community)
- ■ **Umbrella healthcare charities** (supporting healthcare professionals caring for rare disease patients)
- ■ **Industry** interested in rare diseases

Fig.2

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PROJECT ROADMAP

01

Partner with the rare disease community

We are here!

02

Explore, research, engage with potential academic or industry partners

03

Review existing research resources and identify best practice

04

Create tailored resources to facilitate new patient-led rare disease research

05

Consider how rare disease research can be delivered more efficiently

06

Launch an online platform to support new research partnerships

07

Review, advertise, and publish the project findings

08

Decide a long-term, sustainable community management plan

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PROJECT TIMELINE

June – Sept 2023

- Recruit 2 new staff to facilitate project
- Recruit 16 community members & 4 research experts to form working groups

October 2023

- Kick-off meeting 13 October
- Begin outreach & awareness activities
- Recruit website developer

Nov 2023 – Apr 2024

- Review & create patient-led research resources
- Engage the wider community in designing the network and platform

Dec 2023 – July 2024

- Review rare disease research design
- Engage the wider community to improve research methods
- Consider how to support future research

June – Sept 2024

- Programmer workshop to review online platform
- Launch pilot platform

July – Nov 2024

- Promote the network across all stakeholders
- Raise awareness of the network at conferences and events

Sept – Oct 2024

- Community evaluation activities
- Decide model for sustainable community-led management

Nov – Dec 2024

- **Launch network at RareFEST**
- Awareness campaign
- Review process & impact
- Publish reports & lay summaries

Developed with the community, for the community!

It’s vital that the network reflects the diverse needs and interests of the rare disease community. The whole project will be led and developed by people living with a rare disease, their families and carers, patient representatives and advocates. If you’d like to be involved, we’d love to hear from you! You could:

- Join a working group
- Join our consultation team
- Participate in outreach activities
- Join the management team once the network is launched

COULD YOU....

L

BE A LEADER

Can you help co-chair the working group meetings, give the group direction and keep the project on track?

C

BE A CONTRIBUTOR

Can you contribute your lived experience and represent the rare disease community to ensure their voice is heard?

C

BE A CONNECTOR

Could you make introductions to people and organisations who will be able to help with skills, resources or funding?

P

BE A PROMOTER

Will you help us spread the word and ensure this project is able to fulfill its aims and provide meaningful value to the community?

E

BE AN ENABLER

Do you have practical skills, resources, lived experience or an interest in research that you can bring to this project?

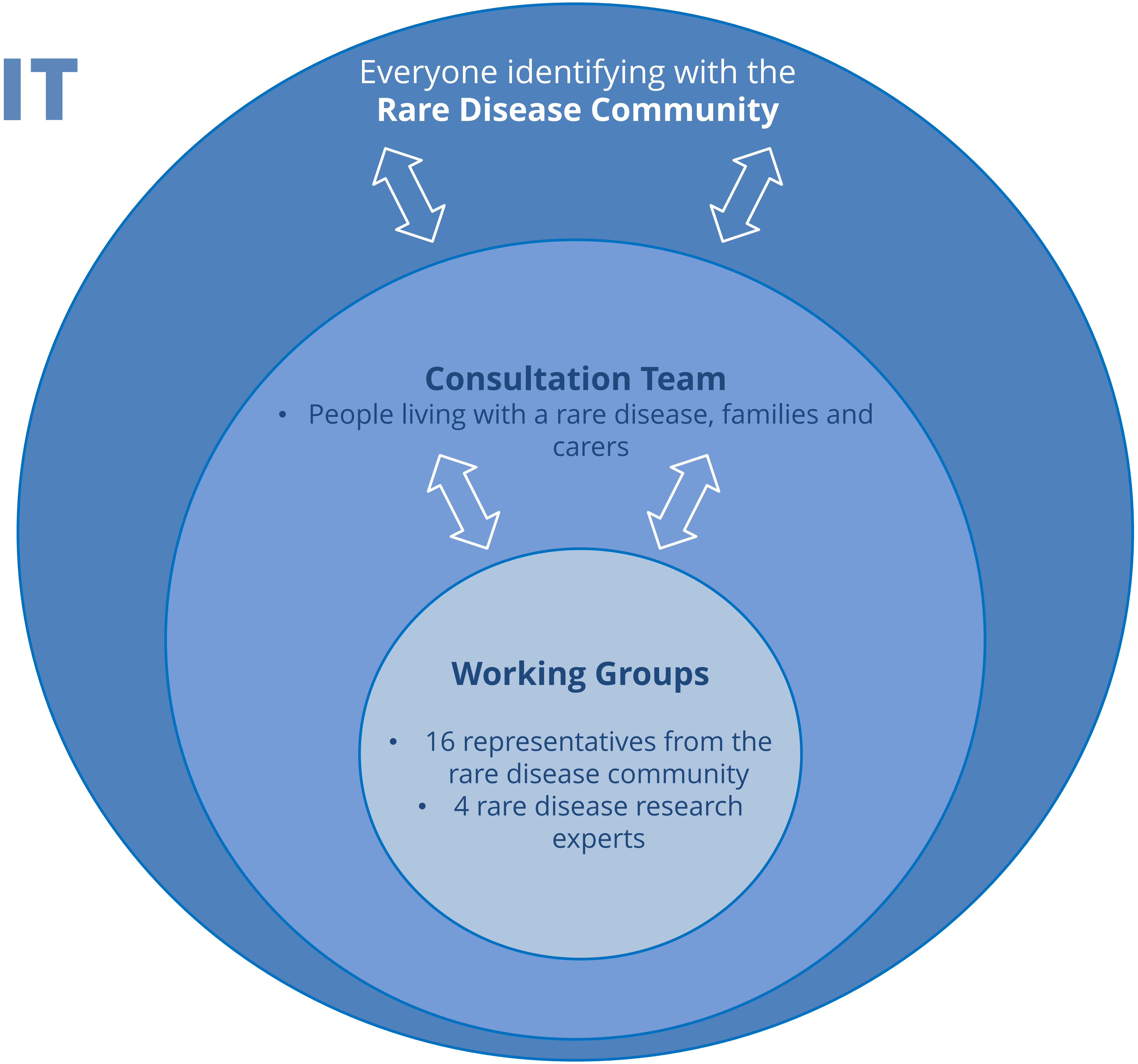
HOW WILL IT WORK?

The project will be led by 2 working groups. The groups will meet regularly and have specific tasks.

They will be supported by a consultation team who will help shape the activities by sharing their own opinions and experiences.

Everyone in the community will be invited to participate in outreach activities to ensure the network reflects a diverse range of needs and interests.

Once the network is launched next year, a community-led management team will be formed.



Everyone identifying with the **Rare Disease Community**

Consultation Team

- People living with a rare disease, families and carers

Working Groups

- 16 representatives from the rare disease community
- 4 rare disease research experts

WORKING GROUPS

Joining a working group requires **commitment**. You will have to:

- Choose which working group to join
- Attend 4-6 meetings (likely 2 hours each, in-person or virtually) between October 2023 and July 2024
- Complete specific tasks
- Communicate with your team between meetings

You will be paid £25/hr for your time spent on the project. You can choose to accept this payment as cash, bank transfer, vouchers, or donate it to a charity of your choice. You will be reimbursed for agreed expenses, including travel, accommodation, and some working from home costs.

Working Group 1 will focus on:

- How the rare disease community can lead their own research
- Identifying potential research partners
- Designing an online platform (website) and registration process

Working Group 2 will focus on:

- Reviewing and creating new resources to support community-led research
- Considering how rare disease research can be designed more efficiently

CONSULATION TEAM & OUTREACH

Joining the consultation team is more flexible. You will be the main point of contact for the working groups, but you can **pick and choose which activities** to take part in. You can:

- Share your own opinions and experiences to shape working group activities
- Review and comment on project ideas and resources
- Test out the online platform prior to launch
- Help with outreach activities, enabling other community members to share their own opinions and experiences in a safe space

Most communication will be through email, but there may be some virtual or in-person events. Depending on the activity, you may be paid £25/hr for your time and reimbursed for agreed expenses.

Participating in outreach activities is the most flexible option and requires the least commitment. We will regularly invite everyone in the community to share their opinions and experiences through anonymous online surveys and at community events. In general, you will not be paid for your time for participating in these activities.

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WHY GET INVOLVED?

01

Contribute to vital research

Turn rare disease research on its head

Build the future of rare disease research

02

Collaboration opportunities

Meet like minded people

Get paid for your time, or fundraise for your charity

03

Raise your charity and your disease profile

Click HERE or scan to register your interest ›

Registering your interest requires you to share your contact details and experiences in an online survey. It will take about 10 minutes to complete. All data is stored in a UK GDPR-compliant database and accessed only by CamRARE and Patient Led Research Hub.

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ABOUT US

The Patient Led Research Hub and Cambridge Rare Disease Network are both based in Cambridge but working nationally and internationally.

We are passionate about network building and stakeholder engagement and providing a platform for patient groups to share their unmet needs with each other and an audience of healthcare professionals, policy-makers, industry representatives and researchers to encourage the development of cross-sector, patient-centered research solutions.

We will provide guidance and leadership throughout the network’s development and management. We will ensure the rare disease community and seldom-heard voices are engaged and involved with appropriate activities. Through our affiliations we will champion the rare disease research network and engage the wider rare disease stakeholder group to interact with the online platform, its members and resources.

Want to learn more?
Have some questions?
Have some ideas?
Fancy a chat about CamRARE or Patient Led Research Hub?

CONTACT US:

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Laura Cowley: lbm28@cam.ac.uk or info@plrh.org

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