



Patient Led Research Hub (PLRH)

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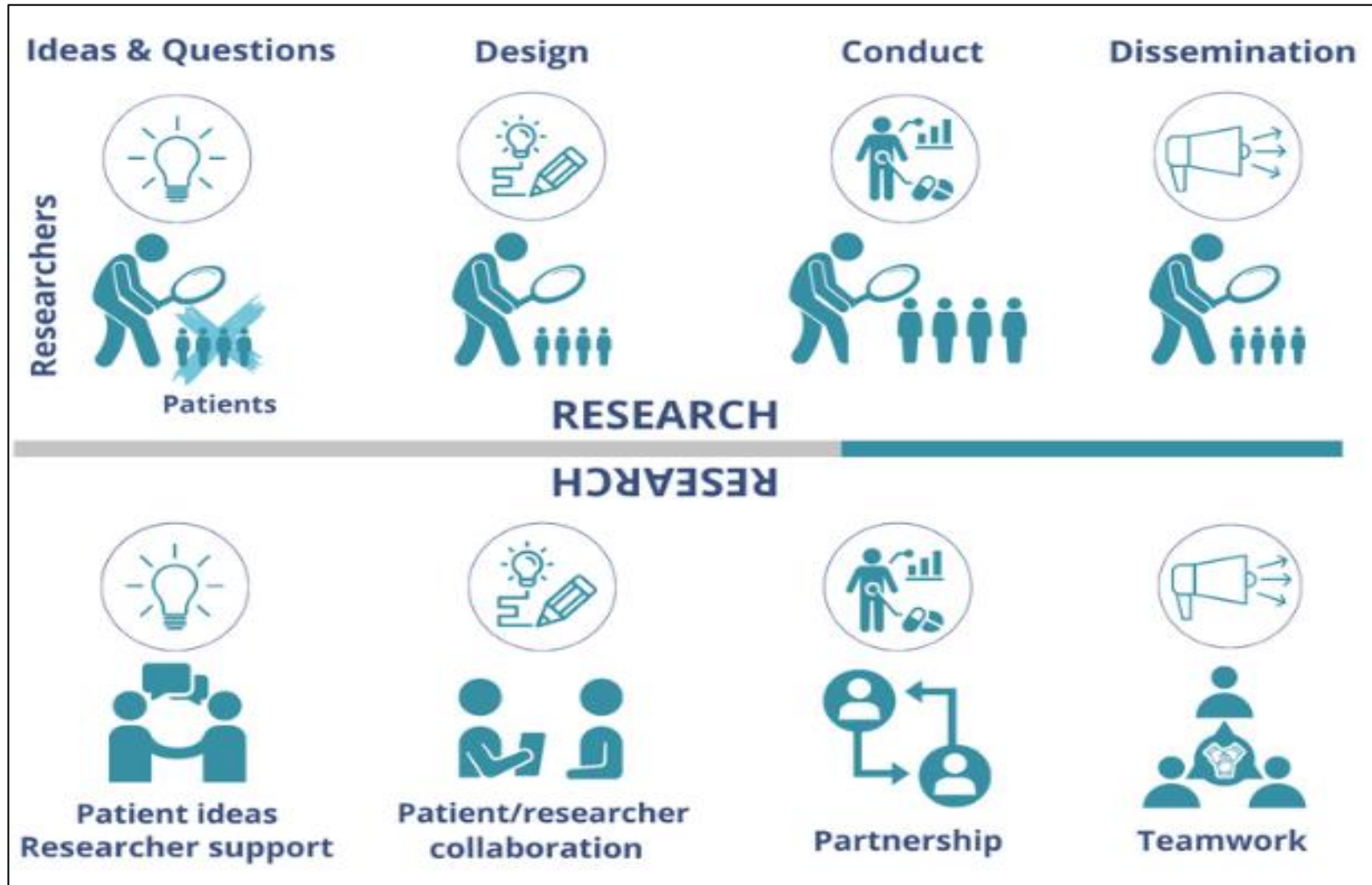
Medical Director Patient led Research Hub

16th April 2024

PLRH: co-producing research



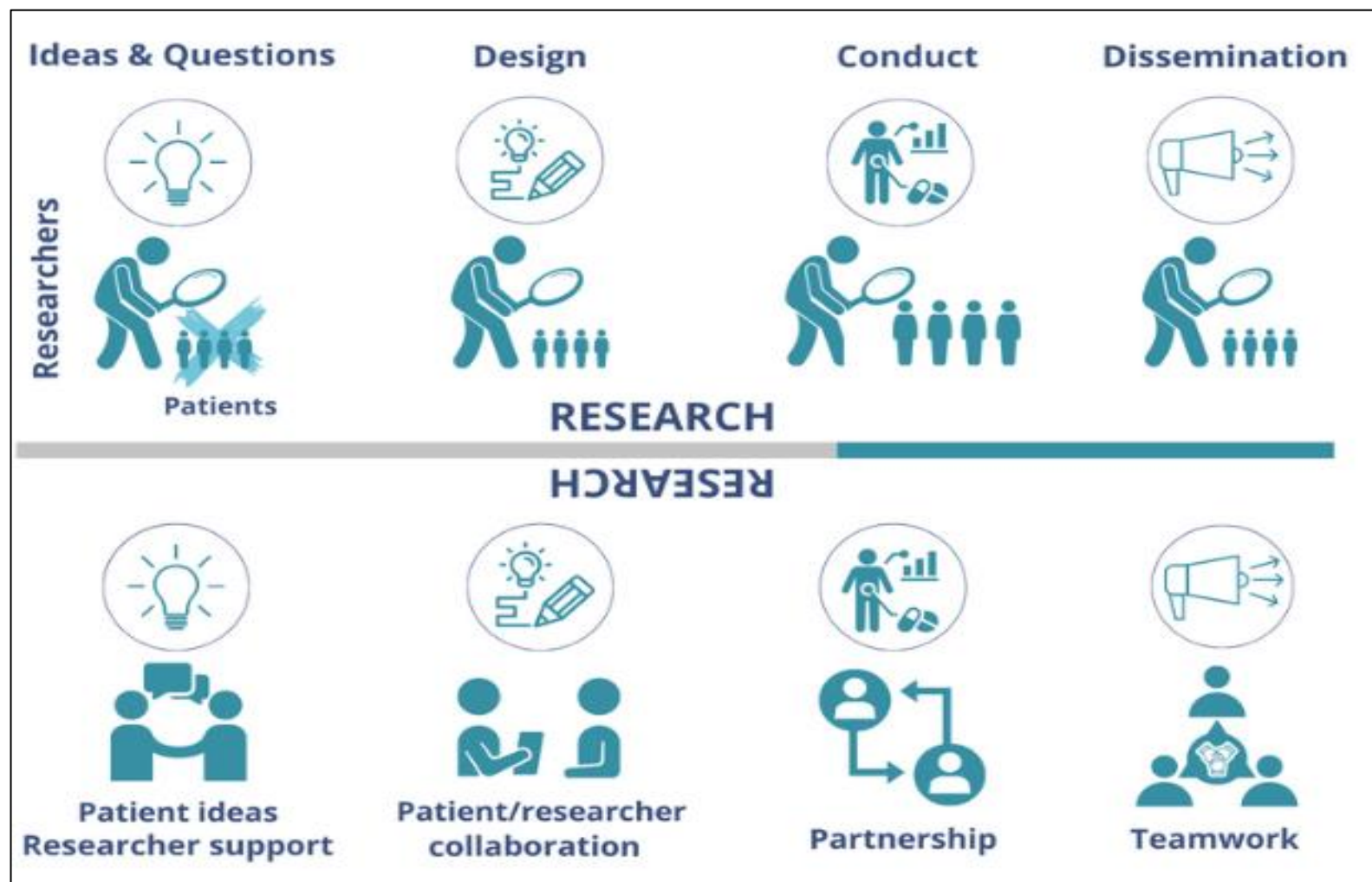
Patient Led Research Hub



PLRH: co-producing research



Patient Led Research Hub



Rare disease research



Patient Led Research Hub



Rare disease community wanted to be involved in **setting research agenda**



Address key priorities which affect patients now, capturing relevant outcome measures



Foster **cross-sector collaboration** to address multi-system rare diseases



Improve research efficiency by designing inclusive trials considering innovative methodology

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Patient Led Research Hub

camRARE
Cambridge Rare Disease Network

+



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Rare Disease Research Network



Rare Disease Research Network

Turning Research on its Head



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Upskill community: resources for research design & delivery

Upskill researchers: to understand community priorities, relevant outcome measures particularly related to mental health & quality of life



Explore acceptable, inclusive methodologies with community, qualitative researchers, biostatisticians, trialists



Expand capacity to facilitate new, patient-centred research including a peer mentorship program and match making facility



Support existing investigator-led research platforms & patient involvement initiatives



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Turning Research on its Head



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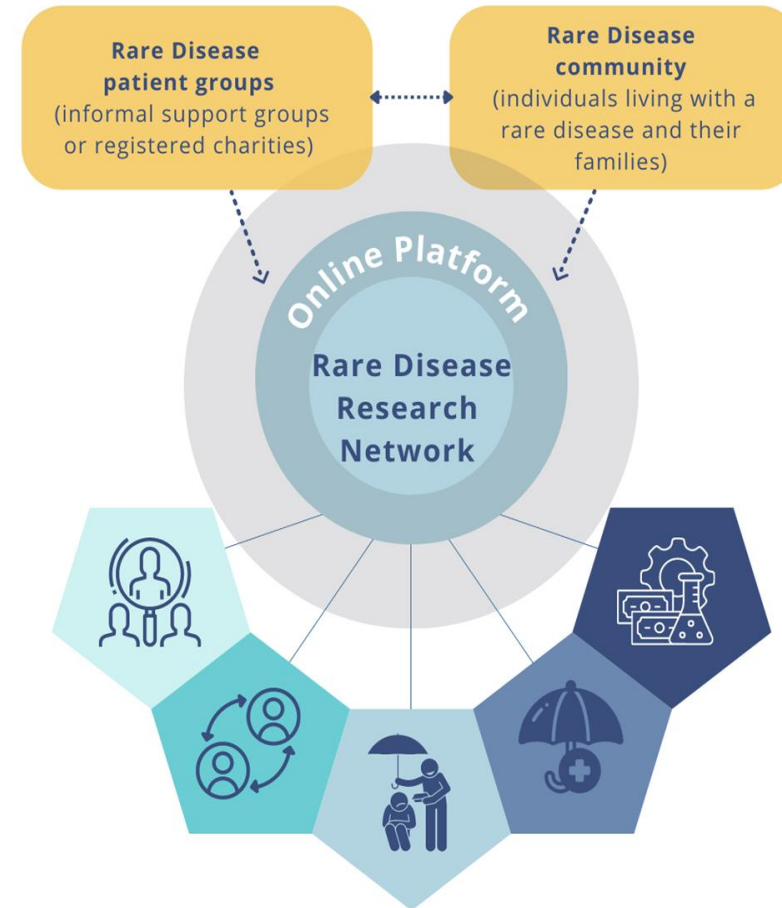
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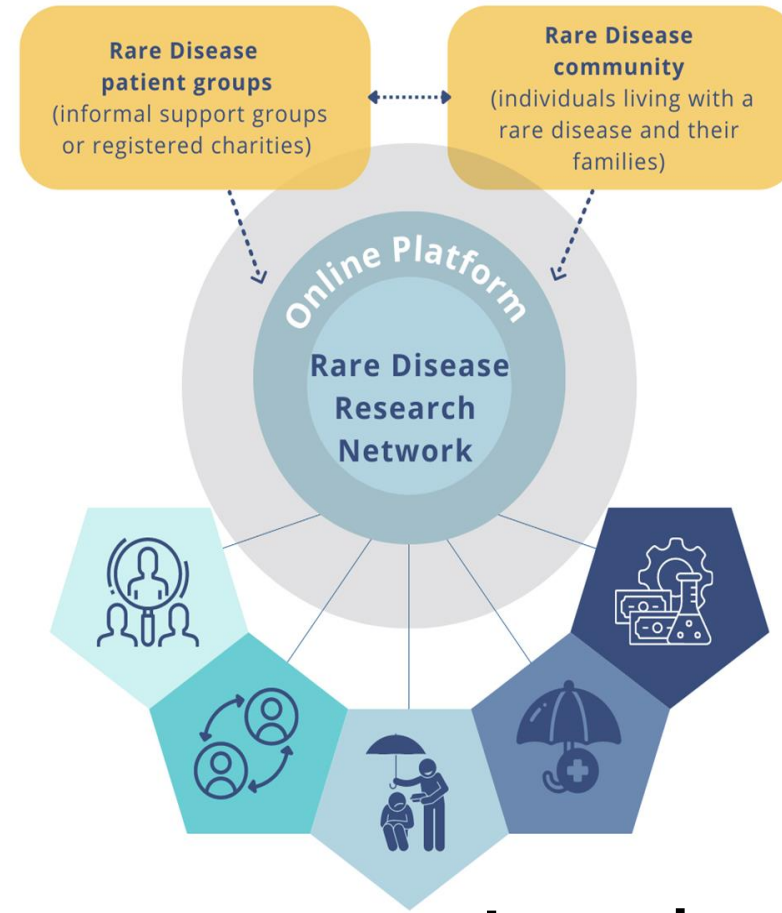
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- Researchers & research groups** interested in rare diseases
- Groups supporting** patient involvement & engagement in healthcare research
- Umbrella rare disease charities** (supporting the community)
- Umbrella healthcare charities** (supporting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

Launches November 2024



Patient Led Research Hub (PLRH)

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Plrh.org