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**The Centre for Community-Driven Research (CCDR)** is a non-profit organisation bringing much needed change to the way we think about community engagement in health and research. Our vision is to facilitate meaningful connection between service providers, research organisations, the non-profit sector, practitioners, industry, government and the communities for which they provide a service or aim to benefit.

CCDR listens to the issues that patients, researchers, government, healthcare and industry partners face and develop solutions - through community engagement - to solve those issues. We do this so that research, healthcare programs, policies and products being developed can reach the patients sooner, and better address the needs of the community.

**Patient Experience, Expectations & Knowledge (PEEK)** is a research program developed by CCDR.

The aim of PEEK is to conduct patient experience studies across several disease areas using a protocol that will allow for comparisons over time (both quantitative and qualitative components). PEEK studies give us a clear picture and historical record of what it is like to be a patient at a given point in time, and by asking patients about their expectations, PEEK studies give us a way forward to support patients with treatments, information and care.

At the completion of studies, sponsor organisations will have access to a study report and complete data-set. Eventually, the report will be made publically available. Study sponsors will have exclusive access to the report and data for a nominated period before it is open to public access. The research protocol and approach remains independently driven by CCDR, however there are opportunities for sponsors to include their own questions that will remain confidential (that is, they will not be published with the public study report)..

PEEK studies include a quantitative and qualitative component. The quantitative component is based on a series of validated tools. The qualitative component is the result of two years of protocol testing by CCDR to develop a structured interview that solicits patient experience data and provides patients with the opportunity to provide advice on what they would like to see in relation to future treatment, information and care. The structured interview has also been designed so that the outcomes of PEEK studies can inform recommendations made in the context of Health Technology Assessment.

**Quantitative research** is conducted as an online questionnaire. Information collected includes:

- Demographic data
- Treatment data
- Access to services
- Experience with clinical trials
- Ranking of values important to patients in decision-making
- Priorities for future treatment, information & care

**Qualitative research** is conducted via telephone by a researcher who is trained and has experience in qualitative research. The first set of interview questions takes the patient through their whole experience from when symptoms were noticed up to the present day. The next set of questions allows patients to reflect on what they would like to see in the future in relation to treatment, information and care, what their messages to decision-makers about their condition would be, and what advice they would give to others recently diagnosed with their condition or disease. Interviews are recorded and transcribed verbatim.

## Community Engagement through PEEK studies

When we commence a PEEK study, CCDR engage all the other non-profit organisations and patient groups in that field to be study partners. Their role within the study is to aid with participant recruitment and our experience has been that patient groups are very open and welcoming of the opportunity as PEEK studies are unique, and help them to understand the needs of the patients that they aim to support. Over the course of the study, there is a sense of anticipation within the community as to the outcomes of the report and we have seen a great opportunity to gain momentum, awareness and strengthen community engagement through PEEK studies. CCDR also ensure that key clinicians and allied health partners are aware of the study and to engage them in the process.

**PEEK 5 year goals:** CCDR aim to seek sponsorship for 10 PEEK studies per year over the next five years as a minimum goal. The areas that we have identified for initial PEEK studies is provided below. We are now calling for sponsors, either individually or as co-funders, to identify and commit to the studies that they would like to sponsor within the next five years on a first come, first served basis without other biases or preferences. There is of course plenty of capacity to take on studies outside these disease areas and once we have the majority of areas covered, CCDR will look at funding studies various rare diseases and then, look to replicate PEEK studies in cohorts outside Australia.

We understand the need for confidentiality in relation to the timing of studies that are aligned with Health Technology Assessment, and to this end, CCDR will keep study sponsors confidential until the launch of each study.

**PEEK long-term goals:** As we collect data, we will store this in a secure data repository and over time, will make this available for research purposes. This will be governed much like any data repository with an application and review process. This means that as questions arise, the data collected can be reanalysed – across a number of disease areas - to answer those questions. A research question might be something like “How does the presentation of treatment options by oncologists differ between cancer types” or “What is the level of anxiety across respiratory conditions and does this impact treatment decisions”. These are just a couple of examples of questions that can be answered through data collected in PEEK studies.

Following the first round of PEEK studies, we then aim to repeat those studies in new cohorts. This will help us, as a sector, to evaluate our collective contribution to patients and the health system and more broadly identify initiatives, clinical protocols, treatments and devices that have had a significant impact on patient experience. Where a new product or protocol has been implemented and there is a more urgent need to evaluate its impact, CCDR are happy to conduct repeat PEEK studies in a shorter timeframe than five years.



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

# BENEFITS FOR ALL STAKEHOLDER GROUPS

**Governments** make decisions that directly impact patients and their families. In the absence of quality information about the experience and expectations of patients, decision-makers are left to make assumptions about the value that patients place on access to care and services, their expectations for the future, and the values that they would like to see included in the decision-making process. Too often, only a small section of the community is invited to provide feedback and have their voice heard. PEEK gives individual patients in metropolitan and rural areas the opportunity to provide feedback and help inform the Government about the needs of their patient population.

**Individual Patients and Their Families:** When a patient is diagnosed with a condition or illness, they naturally search for information about treatment and care options. What is lacking however is information that describes what it is like to be a patient, the challenges, the aspects of treatment and care that have been helpful, what to ask and how to look for help. The PEEK report will be this resource for patients, providing them with an overview of what to expect, and importantly, how to anticipate their own treatment and care needs. We also hope that the reports will make patients feel less alone knowing that others have gone through what they are going through.

**Patient Groups & Non-Profits** need to access quality data and reports about patient experience and expectations to support advocacy initiatives, funding requests, and to help with their own internal strategic planning and evaluation. However, not all groups have research capacity to do this. PEEK provides a cost-effective resource that can be used to develop programs in a timely manner, without needing to expend the time and money to complete a full study of their own.

**Industry:** There is a need, particularly in the context of Health Technology Assessment, to access information that can complement clinical and economic data, that demonstrates patient needs and expectations of future treatments, devices and services. This is what PEEK provides in a systematic, methodologically sound way that allows a cross-section of the community to contribute to the decision-making process in a more equitable, comprehensive way.

**Health Professionals** have a therapeutic relationship with patients and may benefit from reading PEEK reports to get a broader sense of the experience of patients in their local region. This may help them identify some of the challenges patients face or initiatives that have been beneficial, and lead them to identify how they can adapt their own practice to ameliorate some of these challenges.



<b>Infection and parasitic disease</b>	<b>Cancer</b>	<b>Diseases of the blood and blood forming organs</b>	<b>Endocrine, nutritional and metabolic diseases</b>	<b>Mental and behavioural disorders</b>	<b>Diseases of the nervous system</b>	<b>Diseases of the eye and adnexa</b>
Hepatitis B Hepatitis C HIV/AIDS	Bladder cancer Breast cancer Brain cancer Cancer of Unknown Primary Colorectal cancer Head & neck cancer Leukaemia Lung cancer Lymphoma Melanoma Ovarian cancer Pancreatic Cancer Prostate cancer Renal Cell Carcinoma Sarcoma	Anaemia	Cystic fibrosis Diabetes Type 1 Diabetes Type 2 Fabry disease Gaucher disease Pompe disease	Alzheimer disease Anxiety and panic disorders Autism Depressive disorder Schizophrenia	Epilepsy Motor Neuron Disease Muscular Dystrophy Multiple Sclerosis Parkinson's disease Spinal Muscular Atrophy	Cataract Glaucoma Macular Degeneration
<b>Diseases of the circulatory system</b>	<b>Diseases of the respiratory system</b>	<b>Diseases of the digestive system</b>	<b>Diseases of the skin and subcutaneous tissue</b>	<b>Diseases of the musculoskeletal system and connective tissue</b>	<b>Diseases of the genitourinary system</b>	<b>Congenital malformations, deformations and chromosomal abnormalities</b>
Angina Atrial Fibrillation Chronic Heart Failure Heart Attack Hypertension Stroke	Asthma COPD Emphysema GERD	Crohn's Disease Irritable Bowel Syndrome Ulcerative colitis	Dermatitis-Eczema	Fibromyalgia Osteoarthritis Osteoporosis Rheumatoid Arthritis	Chronic Kidney Disease	Downs Syndrome Spina Bifida