

## Consumer Network - Terms of Reference

### Background

The Institute for Physical Activity and Nutrition (IPAN) is a world leading research institute that aims to improve the health and quality of life across all ages and life stages. IPAN's research covers a wide range of physical activity and nutrition research. These include:

- **Biology of Health and Disease** – Understanding how the biological mechanisms behind exercise and nutrition work and how they affect health.
- **Healthy Active Living** – Real-world solutions to increase physical activity in the community.
- **Preventing and Managing Chronic Conditions** – Developing and implementing lifestyle-based solutions to prevent and manage chronic care conditions.
- **Food Nutrition and Health** – Developing quality evidence and using it to tackle the diverse range of food and nutrition issues in the community.

### Purpose

Consumer involvement is an active partnership where consumers work together with researchers, rather than 'to, 'about' or 'for' them. IPAN is committed to consumer involvement being a core part of its research and innovation. The IPAN Consumer Network has been developed as a formal way for IPAN's researchers to involve consumers to design, develop and deliver research that specifically target their needs. Consumers are defined as follows:

**Consumers:** Individuals who are potential recipients/end-users or deliverers of IPAN research outcomes.

*By end-users we mean eg., people with or at risk of health conditions, carers and support people, family, friends, children/students.*

*By deliverers we mean eg., clinicians, teachers, allied health professionals.*

*By IPAN research outcomes we mean e.g., guidelines, programs, strategies, knowledge gain, tools.*

**Consumer representatives:** Someone who voices consumers' perspectives on behalf of consumers. They may be nominated by/be accountable to an organisation of consumers eg., Health Issues Centre.

## **Key Responsibilities**

The IPAN Consumer Network is a group of consumers with a lived experience in a range of health, social and environmental contexts. The network has been established as a way for consumers to provide input/advice to help IPAN design, develop and deliver research that can be used in the real world. Consumers from the network will have their skills, knowledge and lived experience matched to existing and future research opportunities. Examples of the type of research activities that network members may be involved in include:

- Helping with informing research priorities and needs.
- Advising and providing input on consumer issues related to the design, implementation and evaluation of research program/interventions/guidelines/tools (eg., software, wearable devices etc).
- Providing advice on how to write clear patient information and consent forms and support communication of research updates in a consumer-friendly way.
- Providing input into study design and research tools such as clarifying research questions, developing appropriate recruitment strategies, reviewing and commenting on interview questions, questionnaires and data collection methods.
- Providing advice on different ways to send out findings to diverse audience, presenting results back to support groups, jointly presenting findings with researchers at conferences and co-authoring in publications.
- Participating in project steering committees, working groups and specific purpose advisory groups.

## **Membership**

Members of the network will represent the lived experience of many of the health and lifestyle conditions that inform IPAN's research domains. For example, those affected with or by chronic conditions like diabetes, cancer, cardiovascular disease, obesity, dementia and musculoskeletal conditions. Members will also include those across a range of ages and life stages (eg., parents of infants and young adults through to older adults). To promote inclusive opportunities, there will be deliberate and targeted engagement to the following priority groups:

- o Aboriginal and Torres Strait Islander people
- o Culturally and linguistically diverse communities (including established and new and emerging)
- o People who experience social disadvantage living on low incomes
- o Rural and remote communities
- o People living with mental illness
- o People with disabilities

The Consumer Network Coordinator is the point of contact for all network members.

## **Recruitment and Engagement**

Consumers will be recruited to the network by the Consumer Network Coordinator. A range of strategies and communications will be undertaken to recruit and keep consumers on the network. Communication

with the network and between the network and researchers will be managed by the Consumer Network Coordinator.

### **Duration of Involvement**

Consumers on the network can be involved in a one-off research activity or event, and/or medium to long-term research activities. For consumers involved in ongoing activities, such as a committee, participation will be for a maximum term of up to two years from the date of commencement. Consumers involved in large grant projects (eg., 5 years) may continue to take part until the end of the project grant.

### **Operating Procedure**

#### **Working with Children Check**

All Consumer Network members are required to have a valid, or be willing to apply for, a volunteer Working with Children Check (WWCC). As a Victorian organisation, that provides services to children (people under 18 years of age), Deakin University is required to follow the Victorian Child Safe Standards. The University is committed to using the volunteer Working with Children Check, as a screening process for volunteers who may encounter children as part of their role. Network members may have (or apply for) a valid Victorian or relevant Interstate volunteer WWCC.

#### **Conflict of Interest**

Consumers are asked to contribute as individuals with an interest or experience in areas related to IPAN's research, and not as representatives of another group or organisation (apart from those representing the consumer as defined above). Conflicts between a member of the network's public duty to IPAN and a private interest can lead to a conflict of interest. A conflict exists whether it is actual, potential or perceived. The term private interests include not only a member's own personal, professional or business interests, but also the personal, professional or business interests of individuals or groups with whom they are closely associated.

When consumers initially apply to join the Consumer Network, they sign a declaration as part of the application process stating that they understand and agree to disclose any involvement they may have with other organisations, government bodies, companies or individuals which could result in an actual, potential, or perceived conflict of interest with the work they undertake for each research activity.

All consumers involved in a specific research activity must complete an **IPAN Consumer Conflict of Interest Declaration Form**. The declaration outlines details of the COI (if any), including a proposed management plan, that is discussed and agreed upon with the consumer. The management plan will include strategies that are deemed the most appropriate according to the COI.

## Confidentiality

Network members must treat all documents, be it research or governance documents as confidential. Any information obtained during a member's participation should be kept strictly confidential, unless required to disclose such information to a third party by law (eg., to government or law enforcement).

## Support for Network Members

All new members of the network will receive an orientation pack to help them build the knowledge and skills needed to confidently take part in research activities.

Members of the network will also be provided with the following support from IPAN:

- Support and access to online resources and training in consumer involvement in research
- Regular updates on IPAN activities
- Briefing/debriefing support with research staff/IPAN Consumer Network Coordinator

## Remuneration

IPAN may offer remuneration (in the form of a gift voucher) for some research activities to acknowledge and support consumer involvement on a project-by-project basis. Remuneration will be made at the discretion of IPAN and will be based on the funding available either through IPAN or individual research projects. When developing the ***IPAN Consumer Network Remuneration Procedure***, IPAN consulted several consumer payment policies including those produced by Safer Care Victoria, the Victorian Comprehensive Cancer Centre, Queensland Health and Monash Partners Council.

## Review and evaluation of Consumer Network

The network will review and evaluate its performance using key indicators from the ***IPAN Consumer Involvement Strategy***. During the network's first year short term evaluations will be undertaken to check and review progress and performance. An annual review will then take place.

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