

The Centre for Health Exercise and Sports Medicine Consumer and Community Involvement Levels

Levels outlined in the following pages -

- 1: Knowledge Translation Network (KTN) Consumer Member
- 2: Project-Specific Consumer Advisor
- 3: Consumer Research Investigator: Academic-Led Research
- 4: Consumer Advisory Panel Member
- 5: Consumer Research Investigator - Consumer-Led Research

Type of involvement	Description	IAP2* Level of participation & researcher responsibility	Involvement activities	Onboarding & training	Evaluation	Reimbursement/ compensation
Level 1: Knowledge Translation Network (KTN) consumer member	<p>A consumer who is listed on CHESM's email database and receives regular newsletters disseminating information about CHESM research activities.</p> <p>Joins directly via the online registration page OR is a consumer with past involvement in CHESM research and who has said they want to be registered.</p>	<p>Level of participation: Inform</p> <p>Researchers promise: We will keep you informed.</p>	<p>Kept informed via bi-monthly email updates about CHESM research including:</p> <ul style="list-style-type: none"> - invites to participate in studies - promotion of CHESM consumer resources - promotion of research study findings. <p>Receives ad hoc invites to complete feedback surveys related to research ideas/planning.</p>	<p>Onboarding: Completes the online form to join the KTN</p> <p>Training: Nil required</p>	<p>Nil</p>	<p>Reimbursement/ Honorarium: Nil financial</p> <p>Non-monetary benefits:</p> <ul style="list-style-type: none"> - access to CHESMs latest research findings - access to evidence-based resources produced & disseminated by CHESM

<p>Level 2: Project-specific consumer advisor</p>	<p>Typically, a past study participant and/or a Level 1 KTN consumer member.</p> <p>Invited via email by a study coordinator to work on activities specific to a single research study (not a research study participant).</p>	<p>Level of participation: Consult</p> <p>Researchers promise: We will keep you informed, listen to & acknowledge concerns & aspirations & provide feedback on how your input influenced the research.</p>	<p>Project specific.</p> <p>May include consultation on:</p> <ul style="list-style-type: none"> - study protocol design (e.g., intervention design & study procedures) - design of consumer facing materials (e.g., study manuals, exercise handouts, recruitment advertisements) <p>May include input and participation in filming of consumer-facing videos/photos</p> <p>Participation may be via</p> <ul style="list-style-type: none"> - meetings - focus groups - 1:1 think aloud interview - survey - email 	<p>Onboarding: Receives <i>Consumer Involvement Introductory resources</i> including:</p> <ul style="list-style-type: none"> - Role description - Conflict of interest form - Out-of-pocket Reimbursement form <p>Training: Provided CHESM's consumer representative support resources (dependent on role). May include:</p> <ul style="list-style-type: none"> - Consumer & Community Involvement Program's (CCIPProgram) free e-Course^ - Australian Clinical Trials Alliance (ACTAs) consumer involvement video's 'What are clinical trials?'; 'What is randomisation?'^# - Plain Language Statement review guide -Focus Group Ground Rules 	<p>Process evaluation</p>	<p>Reimbursement: Parking costs related to participation</p> <p>Honorarium: Where budget allows for expenses related to consumer involvement, CHESM's <i>Honorarium Schedule</i> will be used</p>
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<p>Level 3: Consumer research investigator: Academic-Led research</p>	<p>A consumer with extensive experience in CHESM research activities.</p> <p>Invited via email or phone by Chief Investigator to join the project team.</p>	<p>Level of participation: Involve</p> <p>Researchers promise: We will work with you to ensure your concerns and aspirations are directly reflected in the research and we will provide feedback on how your input influenced the research</p>	<p>Involved in:</p> <ul style="list-style-type: none"> - developing the research question, methods, trial procedures - result interpretation - formulation of dissemination plans <p>Involved in draft document development:</p> <ul style="list-style-type: none"> - Study protocol - Plain Language Statement - Consent forms - Manuscripts: published protocol & findings - Lay results summaries/ infographics 	<p>Onboarding: Receives <i>Consumer Involvement Introductory resources</i> including:</p> <ul style="list-style-type: none"> - Role description - Conflict of interest form - Out-of-pocket Reimbursement form <p>Training: Provided CHESM's consumer representative support resources including:</p> <ul style="list-style-type: none"> - Consumer & Community Involvement Program's (CCIPProgram) free e-Course^ - Australian Clinical Trials Alliance (ACTAs) consumer involvement video's 'What are clinical trials?'; 'What is randomisation?' - Plain Language Statement review guide - Working with children check (if applicable) 	<p>Process evaluation</p>	<p>Reimbursement: Parking costs related to participation</p> <p>Honorarium: Where a grant budget allows for expenses related to consumer involvement, CHESM's <i>Honorarium Schedule</i> will be used</p> <p>Non-monetary benefits: Named as an investigator on the protocol, relevant grant applications, & in line with authorship guidelines, as an author on associated manuscripts.</p>
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Level 4: Consumer Advisory Panel member	<p>Up to 10 consumers with extensive experience in CHESM research activities.</p> <p>Invited via email or phone by the Centre's Consumer Involvement Strategy Action Group Chair.</p>	<p>Level of participation: Collaborate</p> <p>Researchers promise: We will look to you for advice & innovation in designing and conducting our research and incorporate your recommendations to the maximum extent possible.</p>	<p>Participate in scheduled regular meetings & advise on CHESMs research strategy & future research priority setting.</p> <p>Receive ad hoc invites to provide feedback/input into research planning and activities.</p> <p>One member will be invited to sit on the CHESM Advisory Board and attend annual meetings.</p>	<p>Onboarding: Receives <i>Consumer Involvement Introductory resources</i> including:</p> <ul style="list-style-type: none"> - Role description - Conflict of interest form - Out-of-pocket Reimbursement form <p>Training: Workshop (virtual or in-person)</p>	<p>Process evaluation (annual completion)</p>	<p>Reimbursement: parking costs related to participation</p> <p>Honorarium: This will be a voluntary role. For Advisory Board meeting attendance CHESM's <i>Honorarium Schedule</i> will be used</p>
<p>Level 5: Consumer research investigator:</p> <p>Consumer-Led research</p>	<p>Consumer with research experience.</p> <p>Invited or applies for an advertised position.</p>	<p>Level of participation: Empower</p> <p>Researchers promise: We will provide advice and assistance as requested in line with your decisions for designing and conducting your research, as well as for implementing your findings.</p>	<p>Leads all aspects of research with guidance provided by CHESM employed academics/investigators</p>	<p>Onboarding: Completes a contract for University of Melbourne appointment.</p> <p>Receives:</p> <ul style="list-style-type: none"> - Role description - Conflict of interest form <p>Training:</p> <ul style="list-style-type: none"> - Good Clinical Practice training (mandatory completion) - Working with children check (if applicable) 	<p>Process evaluation</p>	<p>Reimbursement: Receives an hourly rate as per contract</p> <p>Honorarium: nil</p> <p>Non-monetary benefits: Named as lead investigator on the protocol, relevant grant applications, & on associated manuscripts</p>

Footnotes:

- * The research-modified International Association for Public Participation (IAP2) spectrum includes Inform; Consult; Involve; Empower.[1]
- ^ CCIPProgram e-Course ‘Consumer and community involvement in health research’ access: https://cciprogram.org/events_training/cciprogram-e-course-online/ (course duration: 30-minute)
- # Australian Clinical Trials Alliance video access (English): ‘What are clinical trials?’: https://involvementtoolkit.clinicaltrialsalliance.org.au/media/fclpjlxx/toolkit_what-are-clinical-trials.mp4; ‘What is randomisation?’: https://involvementtoolkit.clinicaltrialsalliance.org.au/media/eafe1ok5/toolkit_what-are-randomised-controlled-trials.mp4. “What are clinical trials” is available in multi-languages see: <https://involvementtoolkit.clinicaltrialsalliance.org.au/consumers>

Refernce:

1. Bammer G. Key issues in co-creation with stakeholders when research problems are complex. Evidence & Policy. 2019 01 Aug. 2019;15(3):423-35. doi: 10.1332/174426419x15532579188099.