

November 2021



**Physical Activity** for People  
with **Chronic Conditions**

# Phase 1: Consultation, Planning & Development of PACC

PHYSICAL ACTIVITY FOR PEOPLE WITH CHRONIC CONDITIONS  
(PACC)

PRESENTED TO CORE STAKEHOLDER GROUP,

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# 1. INTRODUCTION

This document comprises the report of a planning and consultation process undertaken on behalf of the Core Stakeholder Group of the Physical Activity for People with Chronic Conditions (PACC) initiative. The process was undertaken between April and October 2021. It involved a series of review and planning discussions by the aforementioned Core Stakeholder Group, alongside a consultation process that engaged with people living with a variety of chronic illnesses, health and social care professionals and community-based exercise providers.

## 1.1 PACC

The PACC initiative involves a multi-stakeholder collaboration that was initiated in 2021 by the Carlow, Waterford<sup>1</sup> and Westmeath Sports Partnerships with funding secured under the 2020 Dormant Accounts Innovation Fund of Sport Ireland. PACC is currently a one-year programme, in keeping with its current programme of funding.

As an initiative, PACC has evolved from a recognition of:

- the personal and therapeutic benefits of physical activity for people experiencing ongoing, chronic health conditions; and
- limited opportunities for people with chronic health conditions in Ireland to access physical activity.

Since April 2021, a Core Stakeholder Group, involving the participating Sports Partnerships; a Patient Reference Panel; the HSE<sup>2</sup>; representatives from Athlone, Carlow and Waterford Institutes of Technology and a representative of clinically supervised exercise service-providers<sup>3</sup> has been created to plan, conceptualise and deliver the project.

PACC is being delivered over two separate but interlinked phases. Phase I has engaged the Core Stakeholder Group in a developmental and consultative process to inform the design and implementation of a series of pilot initiatives in Phase II. These pilot initiatives will test new ways of working with a view to developing more effective and more integrated approaches to increasing physical activity opportunities for people with chronic conditions. A Logic Model, offering a one-page summary of the PACC initiative and its vision for change is appended with this report as Annexe I<sup>4</sup>.

This report emerges as the primary output of Phase I of the project.

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<sup>1</sup> Waterford LSP administered the project on behalf of all partners.

<sup>2</sup> Through its Healthy Eating and Active Living Programme

<sup>3</sup> Exwell.

<sup>4</sup> This document was agreed by the Core Stakeholder Group at its first meeting in April 2021.

## 1.2 REPORT STRUCTURE

The remainder of this report is presented in a further four chapters as follows:

*Chapter 2* provides an outline of the methodology undertaken in delivering Phase I of the PACC initiative. It describes the review and planning work of the Core Stakeholder Group and the operation of a Patient Reference Panel, while also outlining the manner in which a broader stakeholder consultation was undertaken.

*Chapter 3* summarises the priority themes to emerge through the stakeholder consultation process. These themes have ultimately informed the direction of Phase II and its emerging pilot projects. Given the significance of the consultation process, chapter 3 is the longest chapter of the report.

*Chapter 4* outlines the manner in which PACC has responded to the priority themes identified during the consultation process and summarises three pilot projects that will be undertaken as the core activity of PACC during Phase II of the initiative.

The report concludes with some final remarks in *Chapter 5*.

Please note that, throughout the report, the terms *people living with chronic conditions*, *end users*, *service users* and *patients* are used interchangeably, with all terms referring to the target group of this initiative, namely people with chronic conditions whose physical activity needs are the subject of the PACC initiative. Similarly, reference is made to people with chronic conditions, chronic diseases and chronic illnesses, all of which refer to long term conditions which can be treated but not cured<sup>5</sup>.

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<sup>5</sup> <https://www.hse.ie/eng/about/who/population-health/population-health-approach/population-health-chronic-illness-framework-july-2008.pdf>

## 2. DELIVERY OF PHASE I: APPROACH & METHODOLOGY

There have been three core elements to the delivery of Phase I of PACC. These were:

- the establishment and facilitation of a multi-sectoral Core Stakeholder Group, responsible for conceptualising, planning and delivering PACC;
- the establishment of a patient reference group;
- the implementation of a stakeholder consultation process.

### 2.1 CORE STAKEHOLDER GROUP

Reference has been made above to the establishment, in April 2021, of a PACC Core Stakeholder Group. Membership comprised Carlow, Waterford and Westmeath Sports Partnerships; a Patient Reference Panel; the HSE; representatives from Athlone, Carlow and Waterford Institutes of Technology and the Director of ExWell. The group, which was established as a multi-stakeholder structure with the function of planning, conceptualising and delivering the project, worked alongside an external facilitator to an agreed Terms of Reference (TORs). The Core Stakeholder Group TORs are appended to this report as Annexe II.

In fulfilling its Phase I function, the Core Stakeholder Group met on a total of nine occasions<sup>6</sup>. Table 1 below offers a summary of outcomes achieved and decisions taken during each Core Stakeholder Meeting. Further detail is offered in respect of the work of the core group in subsequent sections of the report.

**Table 1: Summary of Core Stakeholder Group Meetings and Deliberations**

Meeting	Date	Summary of outcome
1	29 <sup>th</sup> April 2021	<ul style="list-style-type: none"><li>• Induction of Core Stakeholder Group</li><li>• Review of background to PACC</li><li>• Agreement of PACC Project Logic Model</li><li>• Agreement of TORs for group's operation</li><li>• Consideration of approach to project implementation</li><li>• Commitment to a stakeholder consultation process</li></ul>
2	12 <sup>th</sup> May 2021	<ul style="list-style-type: none"><li>• Agreement to establish a patient reference panel as an integral feature of the project</li></ul>

<sup>6</sup> Even though it was originally envisaged that the group would meet on a maximum of five occasions.

- Agreement that PACC would focus on all chronic health conditions, not just a selection
  - Briefing on HSE Integrated Model of Care for the Prevention and Management of Chronic Disease
  - Examination and discussion of a draft consultation framework for stakeholder consultation<sup>7</sup>
- 3                      27<sup>th</sup> May 2021
- Consideration and agreement of the scope of PACC
  - Agreement to begin consultation process with a small number of service users/people living with chronic conditions
  - Agreement that consultation with other stakeholders would follow engagements with service users
  - Agreement of the need for GP voice to be included in Core Stakeholder Group<sup>8</sup>
- 4                      14<sup>th</sup> July 2021
- Introduction of Patient Representative Panel members to the Core Stakeholder Group
  - Presentation and review of findings from consultations with people living with chronic illnesses
  - Identification and agreement of key themes emerging from consultation with people living with chronic illnesses<sup>9</sup>
  - Agreeing next steps in - and timeline for - the consultation process
- 5                      2<sup>nd</sup> September 2021
- Presentation and review of findings from consultations with health and social care professionals and professionals from the exercise sector
  - Identification and agreement of key themes emerging from entire consultation process with service users, health and exercise professionals
  - Consideration of implications for pilot projects

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<sup>7</sup> See Section 2.3 for more detail in this regard.

<sup>8</sup> Yet to be achieved and an objective of Phase II of the initiative.

<sup>9</sup> See Section 3.1 for more detail.

		<ul style="list-style-type: none"> <li>• Agreement that Core Stakeholder Group members would prepare and submit pilot project concept notes in respect of priority themes</li> </ul>
6	16 <sup>th</sup> September 2021	<ul style="list-style-type: none"> <li>• Review of nine concept notes submitted for consideration by Core Stakeholder Group members</li> <li>• Agreement to develop pilot projects across three themes (Service/Programme Pilots: Model Development &amp; Evaluation; Professional Development of Exercise Providers; Addressing Information and Referral Gaps)</li> <li>• Establishment of three Pilot Project Working Groups to cohere concept notes into three project proposals according to agreed themes</li> </ul>
7	27 <sup>th</sup> September 2021	<ul style="list-style-type: none"> <li>• Examination and review of project proposals submitted to Core Stakeholder Group by Pilot Project Working Groups</li> <li>• Agreement by the Core Stakeholder Group that the proposed projects should proceed as the PACC Pilot Projects</li> <li>• Discussion of potential refinements to be included in each project proposal</li> </ul>
8	10 <sup>th</sup> October 2021	<ul style="list-style-type: none"> <li>• Presentation and review of updates/ refinements/ developments within Pilot Projects</li> <li>• Agreement of Terms of Reference for Pilot Project Working Groups to reflect inclusion of members not involved in PACC Core Stakeholder Group</li> <li>• Agreement of processes for pilot project administration and distribution of pilot project funds</li> <li>• Agreeing next steps, particularly in terms of finalising project budgets and timelines</li> </ul>
9	22 <sup>nd</sup> October 2021	<ul style="list-style-type: none"> <li>• Presentation and review of pilot project partner lists, budgets and timelines</li> <li>• Approval of same by Core Stakeholder Group</li> <li>• Agreement of next steps regarding pilot project initiation and implementation</li> </ul>

## **2.2 PATIENT REFERENCE PANEL**

At its first meeting in April, 2021, the Core Stakeholder Group expressed a commitment to ensuring that the voice of service users/people living with chronic conditions would inform its future deliberations. Arising from this commitment, the Project Facilitator, with support from members of the Core Stakeholder Group, made contact with a number of national patient advocacy organisations to explore the possibility of an ongoing engagement with their respective members.

Two organisations, Multiple Sclerosis Ireland (MSI) and the Irish Heart Foundation (IHF) replied to this request, advising that a number of their respective members would be interested in participation in the project. Interested parties were invited to complete an expression of interest form and return it to the Project Facilitator.

An orientation meeting was organised via Zoom in early July for people living with chronic conditions who had submitted an expression of interest form. This orientation provided information on:

- the background to the PACC initiative;
- the role and function of the PACC Core Stakeholder Group;
- the role and function of the Patient Reference Panel;
- approach to the work and requirements of the Patient Reference Panel.

Following the orientation, six individuals expressed interest in participating in the Patient Reference Panel. A meeting was held with the panel prior to each Core Stakeholder meeting, during which the agenda for the Core Stakeholder Group meeting was reviewed and discussed by Patient Reference Panel members. Thereafter, a number of panel members agreed to participate in the Core Stakeholder Group meeting to represent the voice of all panel members in the Core Stakeholder Group's deliberations. This included deliberations concerning the development of pilot projects.

## **2.3 STAKEHOLDER CONSULTATION**

From the outset of the project, it was agreed that the work programme of PACC would be informed by the opinions and perspectives of those with a stake in improved physical activity opportunities for people living with chronic conditions across the country.

Following its initial meeting, a draft stakeholder consultation framework was prepared and presented to the Core Stakeholder Group for approval. This framework underpinned all consultation exercises and is appended below as Annexe III.

The Core Stakeholder Group decided that:



*“the first step of the PACC consultation process should focus on tracking the journey of a small number of service users from diagnosis to treatment to exercise. Consultation with service users would provide a number of case studies that would assist in pinpointing where gaps currently exist and would identify reasons for people seeking or not seeking out exercise services (PACC Core Stakeholder Meeting, 27<sup>th</sup> May, 2021).*

### **2.3.1 Qualitative Approach**

It is important to point out that this was a small scale consultation exercise, influenced by the time constraints of a one-year programme, and by the need for PACC to progress to the development and implementation of pilot projects in the latter stages of 2021.

As such, it was agreed with the Core Stakeholder Group that the consultation should be underpinned by a qualitative approach. This qualitative approach would engage with the experiences, observations and perspectives of consultation participants through interviews and focus group discussions. As noted above, it was agreed that initial consultations would be held with patients/service-users living with one or more chronic conditions. The findings of those consultations would assist in informing later consultation with health and exercise professionals.

## **2.4 PROFILE OF CONSULTATION PARTICIPANTS**

### **2.4.1 People Living with Chronic Conditions**

Seven *one-to-one interviews* were conducted over May-July 2021 with individuals living with chronic health conditions. All consultation participants were approached through patient representative/advocacy organisations such as MSI; the IHF; the Irish Cancer Society; Cystic Fibrosis Ireland and the Irish Kidney Association. Table 2 overleaf offers a short profile of those interviewed:

A further focus group discussion was held in July with twelve people living with obesity<sup>10</sup>, a focus group that was organised with the assistance of the Irish Coalition for People Living with Obesity.

An approach was also made to West Limerick Traveller Primary Health Care Project, seeking support in accessing the voice of Travellers in the consultation. No Traveller participant was secured for the consultation. However, Community Healthcare Workers in the project, all of whom were Travellers, shared valuable insights on attitudes and behaviours relating to exercise among individuals living with chronic conditions within the Traveller community.

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<sup>10</sup> A mix of male and female, of varied ages and from varied locations throughout Ireland.

Table 2: Profile of one-to-one interviews with individuals living with a chronic condition

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Gender:	<ul style="list-style-type: none"><li>• 4 Female</li><li>• 3 Male</li></ul>
Age:	<ul style="list-style-type: none"><li>• Ranging from 34-60+</li></ul>
Working (Y/N):	<ul style="list-style-type: none"><li>• 1 Full time</li><li>• 3 Part-time</li><li>• 3 not in employment</li></ul>
Location:	<ul style="list-style-type: none"><li>• 3 City</li><li>• 2 Town</li><li>• 2 Village</li></ul>
Membership of Minority Ethnic Group:	<ul style="list-style-type: none"><li>• 0</li></ul>
Active prior to diagnosis and/or aware of the importance of exercise	<ul style="list-style-type: none"><li>• All</li></ul>

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All participants were invited to participate in interviews via Zoom. Interviews were recorded with the consent of participants and typically lasted one hour. An overview of the consultation, along with research questions, was sent to participants in advance to give an overview of the themes to be covered during interviews. Discussions principally covered the following themes:

- advice regarding physical activity following diagnosis, treatment, hospitalisation;
- clarity about the need for taking exercise in the context of rehab and ongoing treatment of condition;
- referral by clinicians to Physical Activity Programmes;
- physical exercise support relevant to respective conditions;
- information and knowledge;
- current exercise Levels;
- factors enabling physical activity;
- factors preventing/limiting physical activity;
- key supports required;
- awareness of others in similar circumstances;
- additional comments.

An initial summary report from consultations with patients was prepared and shared with the PACC Patient Reference Panel before its submission to the PACC Core Stakeholder Group for review and discussion.

### 2.4.2 Health and Social Care Professionals

Fourteen one-to-one interviews were conducted in August 2021 with health professionals interested and involved in efforts to increase the participation of people with chronic conditions in physical activity. All consultation participants were approached through members of the Core Stakeholder Group who drew on their network of contacts. Table 3 offers a short profile of those interviewed:

Table 3: Profile of interviewees in one-to-one interviews with health professionals

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Consultants:	• 3
GPs:	• 6 <sup>11</sup>
Chartered Physiotherapists	• 4 <sup>12</sup>
Advanced Nurse Practitioner:	• 1

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Interviews were conducted by phone and were recorded with the consent of participants. Interviews typically lasted between twenty minutes and half an hour.

In addition, eleven Health and Social Care Professionals from various locations around the country participated over two one-hour focus group discussions involving, for example, Health Promotion and Improvement Officers, physiotherapists involved in cardiac and pulmonary rehab services, diabetes dieticians and others. A further focus group discussion was held over an hour-long period with two Social Prescribers, located in Waterford city and county. All focus groups were facilitated and recorded over Zoom.

A short overview of the consultation was forwarded to all participants in advance of discussions. All interviews and focus groups with medical and social care professionals were informed by key themes emerging from prior consultations with people living with chronic conditions and focused principally on:

- availability of reliable exercise services for people living with chronic conditions;
- examination of working relationships, referral and progression pathways to physical exercise for people living with chronic conditions;
- obstacles and enablers to physical activity for people with chronic conditions;
- consideration of potential solutions;
- resources and supports required to facilitate solutions.

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<sup>11</sup> Covering a range of urban and rural practices.

<sup>12</sup> Of whom two were HSE employees in hospital settings, one of whom worked in private practice and one of whom worked in a private hospital.

All of the health and social care professionals consulted expressed a strong commitment to exercise as a form of treatment, especially in the context of people living with chronic illness. Half of the GPs consulted referred to providing written exercise prescriptions as part of their approach to motivating patients towards physical activity.

### **2.4.3 Community-based Exercise Providers**

Five focus group discussions were undertaken with community-based exercise providers. These focus groups were conducted with the following:

- five LSP Coordinators;<sup>13</sup>
- eight LSP staff and tutors involved with the Carlow, Waterford and Westmeath Sports Partnerships;<sup>14</sup>
- two representatives from Sport Ireland;
- five representatives of community-based exercise facilities, all of whom possessed knowledge and experience of supporting the physical activity of people with chronic illnesses;
- two representatives of Siel Bleu<sup>15</sup>.

The coordinators of Carlow, Waterford and Westmeath Sports Partnerships were central in accessing participants for this element of the consultation.

All focus groups were conducted via Zoom and lasted a maximum of one hour. Discussions were recorded with the permission of participants. An overview of the consultation purpose was shared with participants in advance of the discussions, along with key research questions. As in the case of health and social care professionals, focus group discussions with exercise providers centred on:

- the availability of reliable exercise services for people living with chronic conditions;
- examination of working relationships, referral and progression pathways to physical exercise for people living with chronic conditions;
- obstacles and enablers to physical activity for people with chronic conditions;
- consideration of potential solutions;
- resources and supports required to facilitate solutions.

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<sup>13</sup> This discussion did not include the coordinators of Carlow, Waterford and Westmeath Sports Partnerships, the lead agencies of the PACC initiative.

<sup>14</sup> Comprising a mix of Sports Inclusion Disability Officers (SIDO), Community Sports Development Officers, Tutors and Post Graduate students.

<sup>15</sup> Siel Bleu is a registered charity which offers exercise programmes online and in person in Residential and Day Care, with organisations, in communities and also in private homes.

## 2.5 STRENGTHS AND LIMITATIONS OF CONSULTATION METHOD

The most obvious strength in the PACC consultation methodology was its commitment to a qualitative consultation approach. A central feature of this project has involved capturing learning from those with a critical stake in exercise for people with chronic conditions. The adoption of a qualitative consultation approach facilitated participants to express perspectives, to reflect on personal and professional experience, and to engage in depth with the issues being explored. It allowed for the expression of multiple and, in some cases, contradictory perspectives, all of which were relevant and valuable to the consultation process.

The second obvious strength was that the consultation began by engaging with the patient voice. Conversations with patients/end-users set the context for later engagements with medical, social care and exercise professionals. It grounded the consultation in the lived experiences of people living with chronic conditions and their pathways to physical activity following initial diagnosis.

While the approach to the consultation had a number of key strengths, it is important to note that the findings of this report outline a snapshot of issues impacting on the physical activity of people living with chronic conditions, a snapshot offered by a small number of individuals. It is also important to point out that those findings reflect the opinions of individuals with significant experience, expertise, interest and involvement in the issues<sup>16</sup>. It does not grapple with the views of those unaware of or actively seeking not to engage with the issues in question. It is therefore acknowledged that, in due course, further validation of the findings outlined below would be worthwhile.

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<sup>16</sup> A decision taken by the PACC Core Stakeholder Group to expedite the consultation process, mindful of the one-year timeframe for the PACC project.

## 3. CONSULTATION FINDINGS

The purpose of this chapter is to present the key findings from the aforementioned consultation process. The chapter is divided into four sections:

- the first section summarises the key findings from consultations with people living with chronic conditions;
- the second section summarises the key findings from consultation with health and social care professionals;
- the third section presents a summary of key themes emerging from consultation with exercise professionals; and
- the final section draws together the key learning from all stakeholder consultations to identify principal themes which have informed the development of Phase II of PACC.

### 3.1 THE VIEWS OF PEOPLE WITH CHRONIC CONDITIONS

Reference has been made above to the process undertaken to engage the views of a small number of people living with chronic conditions. While a wide variety of issues were discussed during these interviews, four primary themes emerged consistently in one-to-one interviews. These were:

#### ***3.1.1 Advice regarding physical activity following diagnosis, treatment, hospitalisation was minimal***

Patients interviewed highlighted the importance of support, guidance and information in building their confidence around physical activity, particularly in the immediate aftermath of a diagnosis with an ongoing, underlying health condition. However, all patient participants in the consultation noted that advice received was minimal, more stressing the importance of taking exercise or, in some cases, stressing the importance of building exercise up slowly. However, there was little direction on the type or level of physical activity individual patients ought to be taking.

It was noted that hospital-based physiotherapists were the main source of guidance immediately following diagnosis and initial treatment, with two of the research participants advised on a programme of activity/exercise to follow at home. The other participants received no advice on a particular schedule of exercise.

A number of the consultation participants referred to what they considered to be assumptions made in hospital about patient capacity for physical activity. For example, one consultation participant who had suffered heart failure explained;

*“I felt that the main concern of the medical professional was around your stereotypical heart patient – the older, the ones in the bed, the ones not taking exercise before their cardiac event. And the medics worked with them to change their behaviour. But, if you were active*

*before your illness, it felt like they saw you as fine. There was no guidance around the fact that you may have been doing too much in the build up to your event.”*

### **3.1.2 Gaps in Referral<sup>17</sup>**

None of the consultation participants was referred to any form of physical activity programme – either hospital-based or community-based. This included the aforementioned patient who had experienced heart failure and who sought a referral to cardiac rehab but did not receive one. As another patient noted:

*“Advice shouldn’t be just about what you need to do but where you need to go.”*

### **3.1.3 Personal Capacity**

All participants highlighted their lack of knowledge on the appropriate levels and nature of physical activity that they should be taking. The personal capacity of those participants to find information for themselves emerged as key in the experiences of all participants, along with personal motivation, to reduce the health risks of their respective conditions. All were taking regular exercise but most physical activity was self-directed.

Knowledge of community-based exercise provision was extremely limited among consultation participants with a number commenting on patients’ frequent reliance on good luck to access the right type of support. One participant referred to finding a gym specialising in service to people with chronic illnesses and disabilities via a social media platform:

*“I had the good good fortune of finding a gym that specialises in people living with chronic illnesses and disabilities. It’s suitable to my needs and I get to use it four of five times a week. I have an unlimited package that costs me €60 a month. It seems to have a wide range of people with underlying health conditions. A mainstream gym wouldn’t suit my condition. I had tried a mainstream gym before but I didn’t stay.”*

### **3.1.4 The role of Patient Representative/Advocacy Groups**

All but one participant involved in one-to-one consultation interviews referred to the importance of patient representative organisations as a key source of information and support, especially in the context of physical activity. For example:

*“I did a Move Smart Programme before Christmas. It’s a programme tailored specially to each individual’s need. You have to fill out a questionnaire and do an interview in advance. It runs in a group of six, all with more or less the same ability levels. I got the link from MSI.”*

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<sup>17</sup> The issue of referral is addressed in much greater detail in Section 3.2, documenting the consultation feedback from health and social care professionals.

*“I follow online workouts from a fitness trainer with the IHF. The service is provided free.”*

*“MSI started up physio-led strength and fitness classes online and I joined these.”*

*“I looked up the web and have relied on the ICS<sup>18</sup> website a lot. ICS’ advice on how to look after yourself has helped me. They have a very good helpline. I got advice on fitness apps that might be helpful, apps that would be pitched at beginners.”*

### **3.1.5 Range of issues affecting people living with obesity**

The consultation focus group facilitated by the Irish Coalition of People Living with Obesity illustrated a spectrum of obstacles that participants highlighted as impacting specifically on the exercise opportunities of people living with obesity. Among others, critical issues highlighted included:

- participants’ constant experience of pain and the difficulty taking physical activity while contending with ongoing, considerable pain;
- building on the above, the need for people living with obesity to have realistic targets when taking exercise;
- the inadequacy of basic exercise infrastructure for people living with excessive weight (e.g. participants highlighted the value of hydrotherapy while noting the need for stairs to enter into pool rather than a ladder);
- challenges of cost, travel and transport to exercise programmes<sup>19</sup>;
- embarrassment and feelings of self-consciousness, illustrated through participants’ fear of public dressing rooms and feeling exposed in exercise settings;
- concerns regarding a lack of empathy and understanding among medical professionals particularly doctors<sup>20</sup>;
- the lack of referral of people living with obesity to exercise programmes with participants simply being told to lose weight.

Participants argued the need for specific responses that matched the complexity of need presented by people living with excessive weight.

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<sup>18</sup> Irish Cancer Society.

<sup>19</sup> Participants in the focus group noted that people living with weight tend to be economically compromised.

<sup>20</sup> A number of participants referred to feeling lectured by health professionals instead of supported. It was suggested that there was a real need to educate doctors on how to work with people living with obesity and in particular to reduce judgements expressed by doctors in respect of people living with excessive weight.



### 3.1.6 Chronic Conditions and the Traveller Community

The following quotes from a focus group with primary healthcare workers of the West Limerick Traveller Primary Healthcare Programme also points to some of the primary obstacles that impact on the exercise levels of Travellers living with chronic conditions:

*“After diagnosis everybody is given a plan, especially around diet and exercise. The problem in the Traveller community is sticking to the plan. The main problem is that the community isn’t educated enough about the condition and the seriousness of the condition. In the beginning people are frightened by the illness, then they get used to living with it and forget to follow the plan. They progress for a while, think they are better and then stop following the plan. They don’t persevere.”*

*“A lot then just see the medication as their cure. This is part of the education piece.”*

*“Most Travellers with underlying conditions will go to Google for information about the condition and what they should be doing about it.”*

### 3.1.7 Summary Report

A more detailed summary report of the consultations held with people living with chronic conditions was prepared and shared with members of the Core Stakeholder Group in July. This summary is attached as Annexe IV. Members of the Core Stakeholder Group acknowledged the interconnection of themes outlined throughout conversations with patients, highlighting that issues surrounding a lack of information and referral were underpinned by the lack of appropriate services to which people could be referred or about which information could be given. It was suggested that a central function of the PACC initiative had to involve putting in place services that would fill those gaps.

## 3.2 THE VIEWS OF HEALTH & SOCIAL CARE PROFESSIONALS

The findings to emerge from consulting people living with chronic conditions offered context for consultations with health and social care professionals. The following outlines their primary observations in respect of obstacles to physical activity for people with chronic illnesses:

### 3.2.1 Patient Motivation

The majority of health and social care professionals referred to an ongoing need to motivate patients with chronic conditions to take physical activity. Motivation was noted as a particular concern in respect of patients from poorer socioeconomic backgrounds. Issues concerning the motivation of people from low income backgrounds included references to:

- lack of awareness with one clinician referring to what she described as the “*unworried unwell.*”

- the need for lifestyle change, especially in diet and exercise;
- patients' expectations of receiving a prescription for medication and that medication would solve their health issues;
- concerns about the cost of accessing exercise facilities and programmes;
- concerns regarding travel and transport, with clinicians pointing out that likelihood of engagement in structured physical activity programmes was increased if the programme was run locally.

Health and social care professionals expressed particular motivational concerns with regard to older men, middle aged women and the emotionally unwell who were living with chronic illnesses. These cohorts were described as having significant confidence issues.

#### *3.2.1.1 Maximising Community Facilities*

Building on concerns expressed about the cost of accessing exercise facilities and travel and transport implications, a number of medical professionals referred to need to maximise community facilities and community organisations. It was noted that most community halls across the country remained empty for large parts of each day. It was also suggested that the GAA was present in every community and was most likely to possess the best exercise facilities in any catchment. It was recommended that PACC should explore how it could align with the GAA Healthy Club Programme. Patient support/advocacy groups were considered important players in the context of physical activity for people with chronic conditions, including from the perspective of patient-motivation.

#### *3.2.2 Concerns about Continuity*

A number of GPs, alongside physiotherapists involved in cardiac and pulmonary rehab services, expressed concern about participation slippage among patients following completion of structured programmes. They noted that hospital-based cardiac and pulmonary rehab programmes were extremely beneficial for patients – both physically and socially – while highlighting that these programmes were timebound. These professionals highlighted their difficulty in monitoring patients' continued participation in physical activity and stressed the importance of year-round structured exercise opportunities that go beyond rehabilitation. They cited examples of good practice that included referral of COPD patients to local COPD exercise support programmes following pulmonary rehab, programmes facilitated by the previously mentioned organisation, Siel Bleu. They also mentioned the HSE Living Well Programme which had provided technology supports to people with chronic conditions to assist their uptake of physical during periods of Covid-19 Lockdown.

### **3.2.3 The Value of Structured Exercise Programmes**

The value of group-based, structured exercise programmes was endorsed across all consultation engagements with health and social care professionals. Consultation participants referred to improved health outcomes alongside strong social benefits for people with chronic illnesses, including the more reticent patients. In fact, clinicians pointed out that the social element of structured exercise programmes was as important to the mental wellbeing of patients as to their physical wellbeing. It was noted that the collective engagement of patients in exercise programmes offered greater encouragement, motivation and reassurance to patients. They were also considered important in informing patients where to start on their respective exercise journeys and informing them how far they could push themselves when undertaking activity.

While citing the importance of structured programmes, consultants and GPs alike emphasised the importance of health professionals being aware of programme availability in the community and the importance of them being able to trust the quality and safety of those exercise programmes.

### **3.2.4 Referral**

Health and social professionals who participated in this consultation process expressed the desire to refer patients onward to ongoing activity services and programmes. Trust of exercise-service providers, however, emerged as the critical concern of health professionals in respect of referring patients to structured physical activity programmes. It was noted consistently across consultation participants that, for a medical practitioner to refer a patient to an exercise programme or provider, s/he would have to:

- know what is available
- trust what is available
- experience an efficient referral process that would not make excessive time demands.

#### **3.2.4.1 Information**

GPs, consultants and physios consulted with referred to significant concern about what they perceived to be an absence of services to which they could safely refer patients. In particular, they expressed concern about having to rely on community-based or private gyms and raised questions about the capacity of these providers to meet the exercise needs of people living with chronic conditions in a safe and trustworthy manner. Clinicians who tended to refer patients to exercise services referred only to providers they knew and generally trusted.

In response to trust and safety concerns, clinicians emphasised the importance of clear and up-to-date information on service-availability. They pointed to the importance of information about:

- the services that were in existence in their respective localities;

- staff training and qualifications and whether or not it was safe to refer patients with chronic illnesses to those services; and
- clarity on how those services would meet the diverse needs of patients with chronic conditions.

They also emphasised the importance of information through formal channels, expressing concern about simple word of mouth information sources. The potential of social prescribers as a trusted information-source was repeated across interviews and discussions. Social prescribers were viewed as:

- having access to up-to-date knowledge of services in the localities in which they serve;
- having positive working relationships with referrers and with clients alike;
- effective at identifying options for clients that would match their range of needs, not just the physical conditions for which they were being referred;
- potential connectors between health professionals and exercise providers in a manner that would meet the needs of both sectors and the clients they both wished to serve.

Health professionals also noted that the onus was on exercise providers to make them aware of the nature of their services and of the safeguards in place to protect the health and wellbeing of their patients. It was suggested in a couple of conversations that the LSP network might also play a useful role in this regard.

#### *3.2.4.2 The importance of ongoing information*

For the information and referral process to be effective, it was noted that information-exchange should be ongoing and not a simple one-off exchange. In particular, GPs noted that if they were to refer a patient to an exercise programme, it would be beneficial to get feedback on patient progress. As one GP stated:

*“Why would one prescribe if progress can’t be measured?”*

An ongoing information sharing loop between clinician and exercise-provider was described as reassuring for the clinician and centrally important for the upkeep of patient motivation. It was suggested that patients’ physical activity progress could become a natural part of discussion when a patient would visit their GP and would enhance exercise behavioural change.

#### *3.2.4.3 Efficiency of Referral*

A number of the health professionals interviewed noted that clinicians were frequently asked to sign forms when referring patients to exercise provision. GPs in particular referred to form filling being cumbersome, particularly when time with patients was limited. Consequently, all highlighted the importance of keeping referral processes simple and efficient.

### 3.2.5 *The GP role*

Across consultations with health and social care professionals, reference was made to the significant role of GPs in promoting and motivating patient participation in physical activity. Interviewees frequently referred to the importance of a patient's GP being enthusiastic about the health benefits of exercise. GPs are trusted by their patients and their advice is listened to over and above other professionals. It was suggested that exercise prescription was as important as the prescription of medication in the context of people living with chronic conditions. The greater the promotion of the health benefits of exercise, the greater likelihood of patients engaging in physical activity. It was also noted that the promotion of physical activity was not uniform across GP practices.

## 3.3 THE VIEWS OF EXERCISE PROFESSIONALS

Group discussions with representatives of the exercise sector raised five priority themes as follows:

- LSPs have limited knowledge and interaction with people living with chronic conditions;
- there exists debate within the LSP network regarding the role of LSPs in working with people with chronic conditions;
- there is a considerable divide between the health and exercise sectors, particularly in relation to people living with chronic conditions;
- there is a recognition among exercise professionals of knowledge, skill and capacity deficiencies within the sector relevant to working with people with chronic conditions;
- there are a small number of exercise providers that specialise in working with people with chronic conditions.

### 3.3.1 *LSPs*

Consultation with LSP coordinators and staff revealed that LSP involvement with people living with chronic illnesses was limited. It was noted that people living with chronic conditions were not a priority target group in most LSPs across the country. LSP tutors and staff acknowledged that they had limited knowledge of chronic conditions and felt that it would be important that provision for people with chronic conditions would be tailored to their respective needs and functional capacities.

A number of consultation participants noted that their respective LSPs had acted as supportive partners in physical activity programmes for people with chronic conditions, while also noting a reluctance to lead any projects concerning underlying health conditions.

LSP personnel highlighted that there was a growing recognition of chronic illnesses within the sport and recreation sector and that knowledge and expertise in the sector was growing. It was noted that gyms and leisure centres were increasingly adaptive to the varied needs of clients.

### **3.3.2 Debate regarding the Role of LSPs**

Discussions with LSP personnel and with Sport Ireland emphasised that the role of LSPs was to promote participation in physical activity. That role included an element of contributing to health and wellbeing. However, in the context of physical activity and people living with chronic conditions, the need for clarity was expressed concerning the diverse responsibilities of the HSE and those of LSPs. LSP personnel highlighted that their primary emphasis was on the coordination of physical activity groups for key target populations, as identified by Sport Ireland. Their role was to signpost services and not to engage in direct delivery, particularly to cohorts that they contended fell under the umbrella of health services. LSPs generally saw themselves as partners with the HSE on a range of collaborations concerning people with chronic illnesses. The majority did not see their role as leading service-delivery for people with chronic conditions.

### **3.3.3 Divide between the health and exercise sectors**

Concerns were also raised regarding the relationship between clinicians, especially GPs, and local exercise programme providers. The relationship was described by one group of exercise professionals as “very contentious.” These providers highlighted the difficulty of getting GP endorsement of locally-based exercise programmes, especially in situations where exercise providers were skilled in the area of chronic illnesses.

Exercise professionals emphasised the importance of an enhanced relationship between health and exercise professionals, especially with GPs. It was suggested that, if the medical profession was satisfied with a particular programme or service for people with chronic conditions, then uptake could by people with underlying illnesses could be guaranteed. Exercise professionals stressed the importance of ongoing communication between GPs, patients and exercise professionals. As in the case of health professionals, the social prescriber role was seen as potentially valuable in enabling that communication. However, exercise professionals suggested that social prescribers were likely to refer patients only to exercise programmes approved as safe by GPs. It was noted that a hierarchy of trust exists in relation to physical activity for people with chronic conditions. This needs to be equalised if locally-based exercise professionals are to play a meaningful role in the physical activity journeys of people with chronic conditions.

### **3.3.4 Skill Deficiencies**

Though awareness of the exercise needs of people living with chronic conditions is growing within the fitness sector, it was acknowledged widely in conversations with exercise professionals that there remain knowledge gaps and skill deficiencies in the sector. It was recommended that there was a significant need to upskill locally-based fitness instructors/coaches in working with people with chronic conditions, particularly in areas such as understanding levels of safety, how far to push patients, etc.

Reference was made to a Train the Trainer programme devised by Laois Sports Partnership, the purpose of which was to ensure safe opportunities for people with chronic conditions to exercise with skilled professionals. This project had been piloted and evaluated and, at the time of interview, Laois LSP was seeking accreditation for the training.

### **3.3.5 Good Practice**

Interviews and discussions revealed that there were a number of organisations in operation that specialise in working directly with chronic conditions. These included, for example, ExWell, Medfit and Siel Bleu. It was suggested that there was a need for the sector to learn from these organisations and to assess how the fitness sector could tailor its provision to people with underlying conditions similar to the organisations referenced above.

## **3.4 PRIORITY THEMES FROM CONSULTATION**

Four primary themes emerged consistently across consultations with patients, health and social care professionals and professionals from the exercise and fitness sector. These concerned:

- 
- the availability of structured and supported exercise services in communities;
  - locally based capacity to deliver structured physical activity programmes for people with chronic conditions;
  - the importance of information flow
  - the importance of efficient referral systems.
- 

Though separate concerns, each of the themes is interlinked and success in respect of one is likely to impact positively on others.

Upon review and reflection by the Core Stakeholder Group, the four themes listed above were prioritised as the themes that required PACC project intervention in Phase II of the initiative. A summary of the detail of the four priority themes is outlined below.

### **3.4.1 The availability of structured and supported exercise services in communities**

Across consultations with varied stakeholders the following was endorsed:

- the need for community-based, accessible services about which patients, clinicians and service-providers alike could be confident;
- the value of, and benefit from, group-based exercise programmes;
- the importance of locally-based services (in so far as possible), taking cognisance of issues of transport; rural provision and IT deficiencies.

Mindful of the significant concerns expressed in relation to people with chronic conditions from low income backgrounds and mindful of concerns regarding slippage following completion of subsidised programmes, it was also consistently noted that locally based exercise programmes should be low cost or involve no cost to the end-user.

Accessible services and programmes should be matched to the **functional capacity of patients/participants**. Medically supervised programmes are more important for people who are more ill and more reluctant (subsidised, centralised). Mainstream exercise-provision should be promoted for patients with chronic illnesses who have a routine and who are able to exercise independently (locally based, personal).

### ***3.4.2 Service availability relies on availability of skilled and informed instructors***

Throughout consultations it was acknowledged that increased availability of tailored exercise services for people with chronic conditions was dependent on there being a ready supply of skilled and informed fitness instructors. It was noted across consultations, especially with providers in the exercise and fitness sector, that the leisure sector was adapting and building capacity for engagement with chronic illnesses. Working with patients with underlying health conditions emerged as a growing area of interest within the leisure sector with providers expressing a willingness to play their part. One LSP and a number of private leisure facilities had initiated processes of upskilling. However, in light of the need to build the trust of health and social care professionals in their services, there was widespread recognition within the sector of the need for increased high quality training for exercise and fitness instructors and for this training to be delivered in a coordinated fashion.

### ***3.4.3 Information Flow***

Information emerged as a critical concern across all parties consulted in this consultation exercise, patients, medics and exercise-providers alike. Simply put, it was noted that trust of exercise-provision and referral to physical activity programmes were reliant on an effective flow of information.

Health practitioners interviewed during the consultation questioned why they would refer a patient to an exercise provider if they did not adequately know what would be done with the patient, by whom and how. Several health professionals commented on being unaware of what was happening in the exercise sector<sup>21</sup> with a number noting that they only referred patients if they knew the provider or personally used the provider's service.

It was also recognised in conversations that information on services changes regularly. It was very difficult for health professionals to stay up-to-date with the provision of other services in their communities, mindful particularly of the limited time that health professionals have with patients. In

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<sup>21</sup> With some exceptions.



the context of physical activity opportunities for people with chronic conditions in the community, it was suggested that LSPs, social prescribers and patient advocacy groups might have an important role to play.

It was also noted that information flow, particularly between exercise providers, patients and GPs, should involve an ongoing exchange. GPs, in particular, highlighted the importance of receiving ongoing information and feedback from providers concerning their patients involvement in physical activity, emphasising its value in terms of clinical reassurance and patient motivation. In this context, effective information flow was seen as an important vehicle in promoting partnership between health and exercise professionals and not simply as a one-off exercise as the time of referral.

#### ***3.4.4 Efficient Referral Systems***

Effective information flow emerged as only one part of the equation during consultations. Both health and exercise professionals commented on the need for referral processes to be kept simple. It was suggested that complicated referral processes were likely to decrease the possibilities of referral taking place. Against this backdrop, professionals from both sectors reaffirmed the potential role of social prescribers to enhance referral processes.

## 4. PACC RESPONSE

In response to the primary issues emerging from the consultation process outlined above, the PACC Core Stakeholder Group agreed to establish three pilot projects for implementation during Phase II of the project. The projects in question set out to address priority gaps in:

- community-based service availability by adapting and extending, in accordance with identified needs, an existing model of exercise provision for people with chronic conditions (ExWell) with a particular emphasis on increasing access, reducing dropout, and enhancing communication and exercise referral between health professionals, participants and exercise providers;
- current capacity levels of exercise professionals by designing, delivering and evaluating a broad-based, multilevel accredited training programme that will be recognised by both the clinical and fitness sectors and that will enable exercise professionals to work confidently with people with a wide range of chronic conditions;
- information and referral processes by facilitating a formalised engagement process between healthcare professionals, social prescribers and community-based physical activity providers to increase the participation of individuals living well with chronic conditions within existing community-based physical activity initiatives.

All pilot initiatives have been selected to test new ways of working, capture learning and facilitate future replication and scalability in other areas of the country.

Planning has already commenced on each of the three projects and detailed project proposals and budgets have been prepared. Working groups from within the Core Stakeholder Group have been established, inclusive of a number of partner organisations from outside the Core Stakeholder Group, to plan, guide and implement the aforementioned projects up to March 2022. A Terms of Reference document has been drawn up to guide the development and work of pilot project working groups and this document is appended as Annexe V below.

It is also important to note that Carlow, Waterford, and Westmeath Sports Partnerships will also be applying to the 2021 Dormant Accounts Sport Innovation Fund with a view to extending the timeframe and potential of the selected pilot projects. A short summary of each of the pilot projects is offered below:

## **4.1 PILOT PROJECT (1): ADAPTING THE EXWELL MODEL**

### **4.1.1 Timeframe for Delivery:**

- 18 months
- First phase of project delivery: October 2021 – March 2022

### **4.1.2 Needs to be Addressed**

The needs to be addressed are:

- How to assess the requirements for a successful project in any new location
- Provision of a multi-component and flexible delivery model
- Development of an expanded referral structure
- Development of a detailed awareness campaign
- Development of an anti-dropout process
- Comprehensive impact measurement
- Identification of and engagement with local stakeholders
- Establishing a responsive and robust communication system with referrers
- Provision of rapid access to the programme, removing identified barriers (including transport and participation costs)
- Development of a bi-directional pathway between the programme and community-based physical activity opportunities
- Provision of short refresher programmes to tackle slippage (i.e. loss of benefit after exiting the programme)
- Development of a financially sustainable model
- Development of a PPI (Patient and Public Involvement) structure

### **4.1.3 Projected Outcomes**

The outcomes will reflect the strategies adopted to address the needs identified above. The key outcomes will be

- Improved access to PA programmes for Chronic illness cohorts, either through expanding an existing programme or, preferably, through developing an entirely new programme
- Development of a scalable model, with particular emphasis on the pre-launch evaluation and planning phase
- Collaboration with all relevant local stakeholders
- Enhanced access for all who would benefit, especially those that traditionally do not embrace public health initiatives
- Implementation of an anti-dropout strategy
- increased traffic of programme graduates into community based PA opportunities
- High uptake of refresher programmes
- Establishment of a PPI structure.

#### 4.1.4 Key Deliverables

This project will do the following

- Develop a detailed framework (*see sample in Appendix*) for pre-launch evaluation and planning that
  - will maximise the likelihood of success
  - can be applied to any location in Ireland
- Implement this Evaluation and Planning framework in the chosen location
- Establish the programme and grow it to a sustainable scale
- Establish a PPI structure once the programme is up and running, and invite the PACC patient representatives to fulfil this role in the interim
- Introduce novel graduation and refresher course structures
- Embed impact measurement into the programme processes.

#### 4.1.5 Stages of Development

##### **PHASE 1 (OCTOBER 21 – MARCH 22)**

###### **Phase 1A: PLANNING** (4-6 weeks, Oct – mid Nov 2021)

This phase will involve 2 specific activities, as follows

- a. The design of a general Location Evaluation Framework (crude sample provided in Appendix)
- b. Implementation of this evaluation framework in the chosen location, with associated actions

###### **Phase 1B: PROGRAMME START UP** (mid Nov 2021 – March 2022)

This phase will involve

- a. Signing agreement with host facility
- b. Staff hire
- c. Development and implementation of a detailed and comprehensive awareness campaign
- d. Development of an expanded referral pathway
- e. Getting started ( 2 sessions / week x up to 3 classes per session for group classes, plus satellite centres and on-line offering)
- f. Efficient feedback to and referrers
- g. Development and implementation of an anti-dropout strategy

##### **PHASE 2 (APRIL 22 – MARCH 23)**

Phase 2 will have 5 core projects, running in parallel throughout this period, as follows

###### **2.1 SUSTAINED PROGRAMME DELIVERY**

The ongoing success will depend on maintaining a smoothly operating awareness / referral / recruitment / retention plan

## **2.2 DEVELOPMENT OF GRADUATION PATHWAY**

This will involve identifying and engaging with all appropriate options and compiling a user-friendly resource for participants

## **2.3. MAINTAINING CONTACT WITH PARTICIPANTS**

will be done through participant Zooms, newsletters social medial, post and emails

## **2.45 PROVISION OF REFRESHER COURSES**

Planned 2-3 week short courses will be offered to previous participants, alongside re-testing and / or supported self-assessment

## **2.5 REPORTING**

In this phase, a detailed evaluation of the 18 month programme will be carried out

### ***4.1.6 Working Group Partners***

- ExWell Medical
- Carlow IT
- Westmeath Sports Partnership
- HSE
- Patient Reference Panel

### ***4.1.7 Project Budget to March 2022<sup>22</sup>***

- Funding sought: €50,450
- Projected funding match additional to PACC: €28,150
- Total projected cost to PACC: €29,450

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<sup>22</sup> The budget required to complete this pilot for the 12 months to March 2023 will be applied for under the 2022 Dormant Accounts Innovation Fund Process.

## 4.2 PILOT PROJECT (2): DEVELOPMENT OF A TRAINING PROGRAMME FOR EXERCISE PROFESSIONALS IN THE AREA OF EXERCISE AND CHRONIC ILLNESS

### 4.2.1 *Timeframe for Delivery*

- 18 months
- First phase of project delivery: October 2021 – March 2022

### 4.2.2 *Needs to be Addressed*

The proposed project evolves from the qualitative consultation completed and from recognition that for health professionals to refer patients to physical activity, they need to be confident that those to whom they refer are sufficiently skilled.

The objective is to develop a training programme for exercise professionals in exercise and chronic conditions. This programme will be a broad-based multi-level accredited programme that will enable exercise professionals to work with people with a wide range of chronic conditions that is recognised by both the clinical and exercise fields.

The project will scope out an approach to developing, upskilling and registering the fitness/exercise provider workforce, with a particular emphasis on those working as Exercise for Health specialists.

#### ***Potential to contribute to systemic change;***

The development of this training course will work across all 4 pillars identified in PACC with a particular emphasis on capacity building in both the clinical and exercise fields. It will allow clinicians referring patients with chronic disease to have trust and access to safe exercise professionals and programmes. It will allow exercise professionals to be accredited and trained to deliver to patients with clinical needs.

### 4.2.3 *Projected Outcomes*

#### ***Improved Knowledge and skills of professionals promoting/supporting people with chronic conditions to participate in regular and appropriate physical activity.***

The project will scope out a model that will build exercise professionals' capacity to deal with various schemes in the future and to ensure a satisfactory level of skill for working with risk populations.

The project will result in Increased number of appropriately trained instructors in the community

Will address the gap in capacity and create a recognised and standardised training programme that will create trust and engage fitness professionals, GPs and participants.

Increase capacity of a range of providers to result in increased opportunities for people with chronic conditions to access appropriate exercise opportunities

The project outcome will have value for exercise industry and exercise providers that participate in the training.

#### **4.2.4 Key Deliverables**

The project will seek to address the capacity building needs of emerging graduates and those already working within the fitness industry.

It is proposed that the project would scope out an approach to developing, upskilling and registering the fitness/exercise provider workforce, with a particular emphasis on those working as Exercise for Health specialists. The project would propose a multi-level model that would build exercise professionals' capacity to deal with various schemes in the future and to ensure a satisfactory level of skill for working with risk populations.

The focus of the training will be on functional fitness. This approach will seek to work towards the development of an Irish qualification that would be recognised across sectors. The upskilling programme would be targeted at two primary levels: a lower level of need, i.e. those who need some level of knowledge and skill in addressing risk; and a higher level, focused on individuals seeking to work as exercise for health specialists.

#### **4.2.5 Stages of Development**

***Phase 1 (Nov 21 – March 2022): Engage support resource to facilitate the scoping of the training required including the development of specifications and systems to include:***

- identifying the key players to be involved, particularly in design and delivery;
- the curriculum and infrastructure needed for delivery;
- associated costs and funding mechanisms;
- appropriate assessment and accreditation.

This phase will include establishing a small expert group to input to the process. Desk research, workshop(s), meetings, draft & refined documents to deliver output.

The output of this phase will be a specification document(s) for the next phases.

***Phase 2 (April 22 – March 2023) : Tender out for course design with admin support – replicable and scalable model***

Complete a tender process to appoint a suitably qualified person to develop of the training curriculum, resources, assessment, train the trainers programme informed by specification(s) from Phase 1. The person appointed will, working with the expert group:

- develop the learning outcomes, syllabus and curriculum

- detailed set of standards for delivery and assessment of the programme(s)
- co-ordinate consultation with key stakeholders eg providers (profit & not-for-profit; GP's; health service stakeholders)
- develop the programme content, learning resources and materials, including online hosting to facilitate shared access by team of trainers
- develop and trial a train-the-trainers module

***Phase 3 (April 22 – March 2023): Secure funding for trainers to deliver to wider cohort and evaluate***

Co-ordinate the delivery of the training to a cohort of exercise/fitness professionals and community sport/physical activity facilitators nationally and evaluate. Evaluation to include assessment of impact at client/service user level as they integrate the training into the delivery of programmes. Accredited programme rolled out with a hosting body.

***4.2.6 Working Group Partners***

Key players whose input will be required include the current PACC Core Stakeholder Group, the LSP network, REPs Ireland, the Higher Education sector and Coaching Ireland. As this is a pre-existing structure with cross-sectoral links, it is also proposed that this sub-committee would collaborate with PACC in the development of this project.

***Led by and in collaboration with;***

REPs Ireland, Exercise is Medicine, HSE, Academia/Awarding Body

Programme providers and other stakeholders to be involved at the consultation stage – Irish Society of Chartered Physiotherapists, Irish College of General Practitioners, exercise professionals, etc.

***4.2.7 Project Budget to March 2022<sup>23</sup>***

- Funding sought: €2,293
- Total projected cost to PACC: €2,293

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<sup>23</sup> The budget required to complete this pilot for the 12 months to March 2023 will be applied for under the 2022 Dormant Accounts Innovation Fund Process.



### **4.3 PILOT PROJECT (3): ENGAGEMENT PROCESS BETWEEN HEALTHCARE PROFESSIONALS, SOCIAL PRESCRIBERS AND COMMUNITY-BASED PHYSICAL ACTIVITY PROVIDERS**

#### **4.3.1 *Timeframe for Delivery***

- 18 months
- First phase of project delivery: October 2021 – March 2022

#### **4.3.2 *Needs to be Addressed***

This pilot project proposal seeks to address concerns highlighted by consultation participants as summarised below:

- a) Why would a health practitioner refer a patient if s/he didn't know what would be done with patient, by whom and how?
- b) Health professionals unaware of what's happening in the exercise sector with some exceptions
- c) Generally refer if they know the provider or use the provider's service
- d) Recognition that information changes regularly
  - How to keep it up-to-date
  - Who holds the information on what's available and appropriate?
  - Recognition that health professionals have limited time with patients
- e) Potential of LSPs, Social Prescribers, Patient Advocacy Groups
- f) Why would a health practitioner refer a patient if s/he isn't kept up to speed about the patient's progress?
  - The possibility of feedback on patient progress
  - Ongoing support and not simply at the beginning of the exercise journey
  - Reassuring for clinician and useful for patient motivation
- g) More focused on integration and partnership than simple one-offs

#### **4.3.3 *Projected Outcomes***

This project will seek to increase the access of individuals living well with chronic conditions to existing community-based, non-medically supervised physical activity programmes by developing and strengthening a formalised engagement process between healthcare professionals, social prescribers and community-based physical activity providers. In this way, it seeks to address points A and C above.

In addition, the formal engagement process will be evaluated and refined in further phases of the project. As such, it will include the development of an engagement model that could be replicated in other contexts and between other partners. In this way it will seek to address point d) above.

#### 4.3.4 Key Deliverables

Currently, it is believed that in many contexts the engagement between social prescribing teams and existing community-based physical activity initiatives is ad-hoc and suboptimal. No consistent, formalised engagement procedure exists. As such, this may represent a missed opportunity, where individuals who are living well with chronic conditions in the community, and would benefit from and are interested in attending main-stream community-based physical activity initiatives, are not being supported to do so. This warrants further exploration and interventions that seek to intervene and optimise the engagement processes between key stakeholders (e.g. GPs, social prescribers, community-based physical activity providers) are needed.

This project will focus on those who are living well with chronic conditions within the community. It will consist of a referral strengthening intervention that aims to evaluate a formalised engagement process between community-based physical activity service providers (e.g. LSPs, leisure centres) and social prescribing team(s), primary care centres/GPs and/or the HSE Living Well programme. It is important to note that community-based physical activity initiatives typically do not operate via a referral process currently – in general participants self-register or join a programme as part of a group.

Community-based physical activity service providers (e.g. an LSP in partnership with a leisure centre) will look to actively engage with the social prescribing team to identify individuals who are considered low risk and ready to participate in a number of existing, non-medically supervised community-based PA programmes (e.g. Men on the Move, Women on the Move, Greenway Pedal Pushers etc). This engagement process will include regular (fortnightly/monthly) workshops between both partners to highlight on-going physical activity programmes to which social prescribers would be actively encouraged to regularly refer individuals to. These workshops would also provide opportunities for feedback to be shared with social prescribers in terms of the effectiveness of programmes. This feedback would be group-based in nature and be based on evaluation data physical activity services would be routinely collecting. Both partners would also have the opportunity to discuss barriers to participant engagement that may be encountered and strategies that could be implemented to overcome such challenges.

The project evaluation will seek to adopt a mixed methods approach. A qualitative study will evaluate partners experiences of the engagement process through focus groups and/or interviews. This information will provide important recommendations to support the refinement and replication of the formalised engagement process within other contexts and between other partners. Quantitative data will also be collected in the form of rates of referral by social prescribers to identified, community-based physical activity initiatives and rates of uptake and engagement by participants referred to these programmes.

While the project will not include an intervention to strengthen the relationship between referrers (e.g. GPs, nurses, physiotherapists) and social prescribers, this relationship will also be examined as part of the qualitative study. Referrers will be invited to participate in focus groups and/or

interviews to share their experiences of referral to social prescribing teams with a focus on referrals that would relate to recommending physical activity and how that takes place. It is acknowledged that a limitation of social prescribers' ability to refer individuals to physical activity programmes, may be the number and nature of referrals they receive. While intervening with these stakeholders is not a focus of the project, it is considered important to evaluate this relationship as a potential factor which may influence the success of the formalised engagement process between social prescribers and the community-based physical activity provider.

#### **4.3.5 Stages of Development**

**Phase 1 (October 2021-March 2022)** will seek to....

- Identify relevant stakeholders who would be willing to participate in the project (i.e. a community-based, physical activity provider (e.g. an LSP), a social prescriber(s) and referrers who engage with the social prescribing team (e.g. GPs, nurses, physiotherapists).
- Develop, implement and evaluate the formal engagement process. The specifics of the engagement process would be co-designed by the physical activity provider and social prescriber(s).

**Phase 2 (April 2022-March 2023)** will seek to....

- Build on the results from phase 1 by refining and mapping the formal engagement process.
- Replicate and evaluate the finalised engagement process in other settings (e.g. multi-site implementation across a number of LSPs), and/or between other stakeholders (e.g. a leisure centre and social prescribing team).
- Identify effective strategies to support the optimisation of the formal engagement process (e.g. the role and requirements of an app in supporting referral to community-based physical activity programmes by social prescribers).

#### **4.3.6 Working Group Partners**

Working Group members will be as follows:

- An existing community-based physical activity service, e.g. an LSP
- An academic institution to support evaluation, e.g. an Institute of Technology
- Social Prescribing service
- HSE Living Well Programme
- GP practices
- Physiotherapists
- Participant advisory group

The working group will be led by Waterford LSP while evaluation of the project will be undertaken by one of the Institutes of Technology participating in PACC.

#### **4.3.7 Project Budget to March 2022<sup>24</sup>**

- Funding sought: €10,000
- Total projected cost to PACC: €10,000

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<sup>24</sup> The budget required to complete this pilot for the 12 months to March 2023 will be applied for under the 2022 Dormant Accounts Innovation Fund Process.

## 5. CONCLUDING REMARKS

It has been my privilege to work alongside and resource the deliberations of the PACC Core Stakeholder Group since April 2021, a group of engaged professionals, fully committed to making a meaningful difference in the lives, health, wellbeing and physical activity of people living with chronic illnesses. I would also like to pay tribute to those who participated on the Patient Reference Panel, whose observations and inputs ensured that the voice of those living with chronic conditions was reflected throughout the project.

The process undertaken by the PACC Core Stakeholder Group has been thorough. It has involved a meaningful consultation process, engaging with the views and perspectives of people living with chronic conditions, health and social care professionals and providers within the fitness and leisure sector. All those who have contributed to the consultation were committed to the value of physical activity in the treatment of chronic illness and were extremely thoughtful on strategies required to increase exercise opportunities for people with chronic conditions. In parallel, the PACC Core Stakeholder Group listened to and interrogated all information emerging from the consultation to ensure that the pilot projects outlined above would have the greatest potential for positive impact.

The pilot projects outlined above represent innovative interventions designed to remove obstacles to the participation of people with chronic conditions in regular and appropriate physical activity that match their individual needs, all of which have the potential for replication and future scalability. PACC is premised on a commitment to innovation. The coming together of stakeholders from a variety of backgrounds – exercise, health, academic, patient – to consider, design and develop interventions to increase physical activity opportunities for people with chronic conditions also needs to be viewed as innovative in its own right. The engagement of Core Stakeholder Group members with one another throughout Phase I of the initiative has been respectful and challenging in equal measure. It has presented an example of how multidisciplinary groups can work effectively, recognising the strengths of all group members while also considering systemic gaps that need to be addressed collectively.

I would like to take this opportunity to thank all those who have worked alongside me on this initiative. Particular thanks to the Coordinators of the Carlow, Waterford and Westmeath Sports Partnerships for affording me the opportunity to work on this initiative. Thanks too to both the Core Stakeholder Group and Patient Reference Group members, for their wonderful cooperation with me at all stages of the initiative. Thanks also to those who facilitated and/or participated in the consultation process. Many of those who participated in the consultation exercises expressed interest in learning about the findings from the consultation and PACC's emerging responses. It would be important that feedback would be provided as requested.

Finally, it only remains for me to wish all involved in PACC every success as the initiative progresses to Phase II.

***Neil Haran, Phase I Facilitator, November 2021***

## ANNEXE I: PACC LOGIC MODEL

**Vision:** An Ireland in which people with chronic health conditions have equal opportunity to access regular, appropriate, supported and high quality physical activity in accordance with their needs and interests.

**Mission:** Remove systemic barriers to the participation of people with chronic conditions in physical activity through the creation of a replicable, multisectoral, evidence-informed, collaborative initiative that generates learning and builds on evidenced practice.



**Need:** personal and therapeutic benefits of physical activity for people with chronic health conditions; limited opportunities to access physical activity; need to understand obstacles and develop evidence-informed, systemic solutions, especially vis à vis the impact of social determinants of health.

## ANNEXE II: CORE STAKEHOLDER GROUP TORS

### CONTEXT AND BACKGROUND

Carlow, Waterford and Westmeath Sports Partnerships have initiated a multi-stakeholder collaboration, focused on reducing and removing the barriers that prevent/limit the engagement of people with chronic health conditions in physical activity. The Physical Activity for People with Chronic Conditions Project (PACC) evolves from a recognition of:

- the personal and therapeutic benefits of physical activity for people experiencing ongoing, chronic health conditions; and
- limited opportunities for people with chronic health conditions in Ireland to access physical activity<sup>25</sup>.

The project is funded under the Dormant Accounts Innovation Fund via Sport Ireland

A core stakeholder group, involving the participating Sports Partnerships, patients, the HSE, representatives from Athlone, Carlow and Waterford Institutes of Technology and a representative of service-providers, will be established to plan, conceptualise and deliver the project. Thereafter, PACC will be delivered over two separate but interlinked phases. Phase I will engage the core stakeholder group in a developmental and consultative process that will inform the design and implementation of a series of pilot initiatives in Phase 2. These pilot initiatives will test new ways of working with a view to developing more effective and more integrated approaches to increasing physical activity opportunities for people with chronic conditions.

Terms of Reference for the operation of the Core Stakeholder Group are outlined below.

### PURPOSE

The purpose of these Terms of Reference is to provide a common understanding of the role of the Core Stakeholder Group in the development and delivery of the PACC initiative.

### VISION

The overarching vision for this initiative is to increase opportunities for people with chronic health conditions to access regular, appropriate, supported and high quality physical activity in accordance with their needs and interests, by establishing, planning, implementing and evaluating an innovative project that will:

- generate understanding of the obstacles to physical activity that affect people with chronic conditions;

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<sup>25</sup> In terms of some or all of the following: accessibility, frequency, affordability, relevance and quality.

- test and establish sustainable physical activity pathways for people with chronic health conditions;
- enhance collaboration among health, community, academic and service sectors in enabling physical activity for people with chronic conditions
- create an integrated, multidisciplinary model of good practice in respect of physical activity for people with chronic conditions that will have the potential for future replication in multiple locations across the country and in respect of multiple chronic conditions.

## **PRINCIPLES**

Principles underpinning the Terms of Reference include each of the core group members:

- working in a collaborative, cooperative and transparent way, sharing information, opinion and ideas;
- recognising, reflecting and respecting the differing skills, professional contexts, expertise and values of each member of the group;
- working closely with other relevant stakeholders to ensure the best possible input to the core stakeholder group;
- viewing each member of the core stakeholder group as an equal partner;
- recognising and learning from previous and/or current initiatives with similar objectives;
- learning from the development of this initiative and demonstrating a willingness to share the learning with other interest groups.

## **KEY RESPONSIBILITIES OF THE CORE STAKEHOLDER GROUP**

The core stakeholder group will have responsibility for:

- identifying its aspirations for PACC, as well as guiding and advising on the direction of the project;
- developing a shared understanding of the issues and challenges to be addressed through PACC, and the optimal approaches to addressing those challenges;
- identifying the conditions on which this iteration of PACC will focus;
- informing a consultation process designed to i) generate understanding of the obstacles that impact negatively on the physical activity opportunities of individuals experiencing chronic health conditions and ii) to build an evidence-base for action;
- reviewing and reflecting on research data gathered specifically to inform the group's planning;
- exploring solutions to obstacles experienced by people with chronic conditions, building, where possible, on existing good practice;
- informing the development of outcome-focused pilot interventions;
- working with a planning facilitator/researcher who will resource Phase I of PACC;
- ensuring regular attendance at all relevant meetings;



- ensuring that information used through participation in this initiative will not be used for commercial or competitive advantage.

Core stakeholder group members will be presented with information prior to each meeting, designed to inform their decision-making function. It is expected that all core stakeholder group members will, at a minimum, have read all documentation submitted to them prior to each meeting.

#### **CONFLICT OF INTEREST**

The core stakeholder group will commit to the highest levels of ethics, transparency and accountability in the fulfilment of its function in progressing the PACC initiative. Members will commit to being honest, fair and independent. They will commit to understanding, declaring and managing conflicts of interest (should they arise) and to protecting and promoting the reputation of all parties involved in PACC.

Should a conflict of interest arise in the operation of the group, the conflicted party(ies) will be asked to remove themselves from the discussion until the remaining group members arrive at what they consider to be a fair, honest and appropriate solution to the issue in question.

#### **LEAD AGENCIES**

The lead agencies for the time span of the core stakeholder group are the Carlow, Waterford and Westmeath Sports Partnerships. The lead agencies' responsibilities include:

- contracting a planning facilitator associated with the development of the initiative;
- ensuring a regular flow of information among core stakeholder group members, including minutes of meetings, etc;
- liaising with Sport Ireland on project progress, reporting, managing funding, etc.

The lead agencies contribute to the PACC initiative as equal partners and share equal responsibility for all aspects of the project's delivery.

#### **SCHEDULE OF MEETINGS**

It is proposed that Phase I of the initiative will involve five meetings/workshops of the core stakeholder group over a three month period. It is anticipated that these meetings will:

- *Meeting 1:* secure agreement among core stakeholder group members on the background, rationale, purpose and strategic approach of PACC;
- *Meeting 2:* agree the conditions on which PACC should focus, as well as identifying the type of information required by the core stakeholder group from a planned consultation process;

- *Meeting 3:* review, adapt and ultimately agree a consultation framework and put in place the necessary steps to enable its roll out in community;
- *Meeting 4:* review findings from the aforementioned consultation process and use those findings to consider potential solutions and actions within future pilot projects; and
- *Meeting 5:* review and provide feedback on draft Phase I report.

Meetings in Phase II will be planned within the core stakeholder group arising from the outcome of Phase I.

## **MEMBERSHIP**

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• Clare Lodge, Lecturer in Sports Rehabilitation and Athletic Therapy and Co-Director of healthCORE, Carlow Institute of Technology</li> </ul>      | <ul style="list-style-type: none"> <li>• Eimear Cotter, Project Manager, Healthy Eating Active Living Programme, HSE</li> </ul>                        |
| <ul style="list-style-type: none"> <li>• Ger Walsh, Self-Management Support Coordinator for Chronic Conditions, HSE (CHO 8)</li> </ul>   | <ul style="list-style-type: none"> <li>• Kate O'Connor, Self-Management Support Coordinator for Chronic Conditions, HSE (CHO5)<sup>26</sup></li> </ul> |
| <ul style="list-style-type: none"> <li>• Mairead Cantwell, Lecturer in the Department of Sport &amp; Health Sciences, Technological University of the Shannon: Midlands Midwest</li> </ul> | <ul style="list-style-type: none"> <li>• Martha Jane Duggan, Coordinator, Carlow Local Sports Partnership</li> </ul>                                   |
| <ul style="list-style-type: none"> <li>• Michael Harrison, Head of Department of Sport and Exercise Science, Waterford Institute of Technology</li> </ul>                                  | <ul style="list-style-type: none"> <li>• Neil Haran (Researcher/Facilitator to PACC, Phase I)</li> </ul>   |
| <ul style="list-style-type: none"> <li>• Noel McCaffrey, Director, Exwell Medical</li> </ul>   | <ul style="list-style-type: none"> <li>• Rosarie Kealy, Coordinator, Waterford Local Sports Partnership</li> </ul>                                     |
| <ul style="list-style-type: none"> <li>• Sarah O'Brien, National Lead: Healthy Eating &amp; Active Living Programme, HSE</li> </ul>  | <ul style="list-style-type: none"> <li>• Tony Wheat, Westmeath Local Sports Partnership</li> </ul>   |

## ***Patient representatives***

- |  |   |
|--|---|
| <ul style="list-style-type: none"> <li>• Sheilagh Foley</li> <li>• Sarah Hutchinson</li> <li>• Trevor Gypps</li> </ul> | <ul style="list-style-type: none"> <li>• Clár Ní Mhadóige</li> <li>• Sean Kelly</li> <li>• Hannah Fitzgibbon</li> </ul> |
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<sup>26</sup> Later replaced by Catriona Renwick, HSE

## ANNEXE III: STAKEHOLDER CONSULTATION FRAMEWORK

### INTRODUCTION

This short document presents a framework for undertaking a consultation process as a central component of Phase I of the PACC Initiative. The framework draws its direction from the Logic Model agreed with the PACC Core Stakeholder Group (CSG) during its first meeting on April 29<sup>th</sup>.

The framework outlines objectives of the consultation process; the information it seeks to garner and the manner in which it will be conducted, and will ensure a consistent approach to all consultation activities undertaken.

The framework seeks to answer a set of *who, what, why, when, where, how* questions and is presented under a number of headings as follows:

- Consultation Objectives (the why)
- Information sources (the who)
- Consultation approach (the how and the where)
- Research questions (the what).

### CONSULTATION OBJECTIVES

Drawing on the Logic Model agreed by the CSG, it is proposed that the following are the key objectives of the planned consultation process:

- a) to generate understanding of the obstacles preventing/limiting physical activity levels of people with chronic conditions;
- b) to identify and map existing provision of physical exercise opportunities for people with chronic conditions;
- c) to deepen understanding of referral and progression pathways to physical activity for people living with chronic conditions, and the efficiency of those pathways;
- d) to explore sectoral and cross sectoral synergies (or the lack of) within those referral and progression pathways and deepen understanding of the resultant impacts on physical activity levels of people with chronic conditions.

These objectives will underpin the information to be sought throughout all consultation activities.

### INFORMATION SOURCES

It is recognised that information to satisfy the objectives listed above is held by a wide variety of individuals and agencies. It is proposed that the consultation would garner information from relevant individuals from across the following:

- End users, i.e. people with diagnoses of chronic conditions
- The health sector, i.e. clinicians such as GPs; Self-Management Coordinators; specialist physicians working in area of oncology, COPD, cardiac rehab etc; physios; social prescribers; support group co-ordinators; public health representatives; other
- LSP Coordinators, tutors, relevant staff representatives of Sports Ireland and Healthy Ireland
- Service providers within not for profit organisations, e.g. support organisations such as Asthma Ireland, Irish Heart Foundation, COPD Ireland, Diabetes Ireland, Siel Bleu, Age and Opportunity (Go for Life), etc.
- Commercial providers, e.g. staff of leisure centres (public and private), members of Reps Ireland, Ireland Active
- Academics concerned with physical activity and physical activity for people with chronic conditions in particular.

Given that end users will have a different experiential background and perspective to professionals involved in the area, it is proposed that a different set of research questions would be used for both<sup>27</sup>.

#### **CONSULTATION APPROACH**

The consultation will set out to strike a balance between ensuring optimal reach<sup>28</sup> and sufficient depth<sup>29</sup>. It will prioritise a series of qualitative interactions with representatives of the interest groups listed above. The project facilitator will conduct a series of learning conversations, designed principally to identify issues of significance in respect of the aforementioned consultation objectives.

Qualitative engagements will be conducted remotely, using Zoom or similar platforms and will run for a maximum of one hour. It is proposed that FGDs be undertaken with groups already in existence (in so far as is possible): groups in which participants already have high levels of awareness and trust of one another.

A short report will be prepared following these learning conversations and presented to the CSG.

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<sup>27</sup> Albeit that the core information sought will be more or less the same across all interest groups.

<sup>28</sup> In terms of numbers of to be consulted across each interest group.

<sup>29</sup> In terms of information-quality to satisfy the objectives of the consultation, mindful particularly that the consultation is designed as a learning and project-influencing process.

## ACCESSING CONSULTATION PARTICIPANTS

An essential requirement of the research is that adequate and reliable input is forthcoming from each of the interest groups listed above. The contacts and networks of CSG members will be essential in enabling access to consultation participants and I will require both direction and support from the CSG in this regard.

### ANNEX I: SAMPLE FGD QUESTIONNAIRE – END USERS

<i>Objective</i>	<i>Sample questions</i>
<ul style="list-style-type: none"> <li>• Overview &amp; Introductions</li> </ul>	<ul style="list-style-type: none"> <li>• Can each of you give a short introduction of who you are, where you are from and the condition(s) that affect you?</li> </ul>
<ul style="list-style-type: none"> <li>• Deepen understanding of referral and progression pathways to physical exercise for people living with chronic conditions <i>and</i></li> <li>• Map existing provision of physical exercise opportunities for people with chronic conditions <i>and</i></li> <li>• Explore sectoral and cross-sectoral synergies (or the lack of) within those referral and progression pathways and deepen understanding of the resultant impacts on physical activity levels of people with chronic conditions</li> </ul>	<ul style="list-style-type: none"> <li>• Who first diagnosed you with a chronic condition?</li> <li>• What physical activity schedule were you advised to follow arising from your condition?</li> <li>• Can you describe the referral pathways after diagnosis to physical activity? To whom were you referred for support with your physical activity?</li> <li>• Are you still accessing this support or should you still be accessing this support?</li> <li>• Are the people providing the support trained or specialised in working with your condition? Do you know? Did it ever arise as an issue for you?</li> <li>• Do you pay for the service or is it provided free of charge?</li> </ul>
<ul style="list-style-type: none"> <li>• Generate understanding of the obstacles preventing/limiting physical activity levels of people with chronic conditions</li> </ul>	<ul style="list-style-type: none"> <li>• At this point, what exercise levels should you ideally be taking in light of your respective health conditions?</li> <li>• To what extent do you reach those levels of physical activity weekly/monthly?</li> <li>• What enables you to reach those levels of physical activity?</li> <li>• What prevents you or limits your capacity to undertake the required amount of physical activity?</li> </ul>

- Can you explain how the barriers/obstacles you mentioned impact on your ability to access regular physical activity in accordance with your needs?
- As a service-user, how might referrals and service-provision be improved to enable you take the physical activity you need? What would make the biggest contribution/difference to you?
- Allow participants to add any other issues they consider important to the conversation
- Is there anything else you feel that's important to the conversation that we haven't covered?

## ANNEX II: SAMPLE INTERVIEW/FGD QUESTIONNAIRE – PROFESSIONALS

<i>Objective</i>	<i>Sample questions</i>
<ul style="list-style-type: none"> <li>• Overview &amp; Introductions</li> </ul>	<ul style="list-style-type: none"> <li>• Can you give me a short overview of the work you do and how it relates to the physical activity of people with chronic conditions?</li> <li>• Can you give me some practical examples of that work in action?</li> </ul>
<ul style="list-style-type: none"> <li>• Deepen understanding of referral and progression pathways to <i>and</i></li> <li>• Map existing provision of physical exercise opportunities for people with chronic conditions</li> </ul>	<ul style="list-style-type: none"> <li>• Can you relate to me the referral and progression pathways to physical exercise for people living with chronic conditions and where you, as a professional, fit in those pathways?</li> <li>• What works well in those referral and progression pathways?</li> <li>• What doesn't work so well and why?</li> </ul>
<ul style="list-style-type: none"> <li>• Explore sectoral and cross sectoral synergies (or the lack of) within those referral and progression pathways and deepen understanding of the resultant impacts on physical activity levels of people with chronic conditions</li> </ul>	<ul style="list-style-type: none"> <li>• What working relationships have you with other service-providers in relation to physical exercise for people with chronic conditions?</li> <li>• How well do those working relationships function?</li> <li>• How do these relationships impact (positively or negatively) on the</li> </ul>

- participation of people with chronic conditions in physical activity?
- What improvements are required at sectoral and cross sectoral levels?
- Generate understanding of the obstacles preventing/limiting physical activity levels of people with chronic conditions
- From your perspective as a professional in this area, what are the most significant obstacles (some of which we may have already discussed) that prevent or limit physical activity levels of people with chronic conditions?
- How might these issues be addressed in a systematic way and by whom?
- From where should leadership come in respect of addressing those issues?
- What role should your respective sector play in efforts to overcome these obstacles?
- Allow participants to add any other issues they consider important to the conversation
- Is there anything else you feel that's important to the conversation that we haven't covered?

## ANNEXE IV: PACC PATIENT/END-USER CONSULTATION UPDATE: SUMMARY REPORT TO CORE STAKEHOLDER GROUP (JULY 2021)

### Introduction

This short document presents a summary report of initial consultations with people living with chronic conditions as an integral part of the PACC project. At its meeting in late May, the PACC Core Stakeholder Group agreed:

*“that the first step of the PACC consultation process should focus on tracking the journey of a users would provide a number of case studies that would assist in pinpointing where gaps currently exist and would identify reasons for people seeking or not seeking out exercise services.”* (Minutes Core Stakeholder Group 27<sup>th</sup> May)

It was proposed that those consulted should ideally present with a variety of conditions, have varied functional capacity and be drawn from a cross section of age and cultural backgrounds and locations.

As of 8<sup>th</sup> July, 5 interviews were completed with a further one pending on 13<sup>th</sup> July (and three others being pursued). All consultation participants were approached through patient representative organisations: Multiple Sclerosis Ireland; the Irish Heart Foundation; the Irish Cancer Society; Cystic Fibrosis Ireland; the Irish Kidney Association.

Approaches were also made to West Limerick Traveller Primary Health Care Project, seeking participants living with diabetes and respiratory illness and the Irish Coalition for People Living with Obesity. Both have committed to following up on consultation participants but, at this point, have not reverted with possible contacts.

All organisations that have assisted with the consultation are really interested in the project and interested in the outcome of the consultation.

### Profile of interviewees consulted to date

Four of the five participants interviewed to date were female and one was male. The interviewee scheduled to participate in the consultation on 13<sup>th</sup> July is male.

Those interviewed ranged in age from 34-51 years. Four were working in a mix of full and part-time positions, while one was not in employment. The participants were drawn from various parts of the country with two living in cities; one in a large town and the other two living in rural villages. None of the participants was a member of a cultural or minority ethnic group.



It is important to point out that, prior to their respective diagnoses with a chronic illness, all consultation participants were physically active and all fully understood the importance of exercise to good health.

### **Consultation Method**

All participants were invited to a Zoom interview with Neil Haran, the consultant to PACC. Interviews were recorded with the consent of participants and typically lasted one hour. Questions were sent to participants in advance to give an overview of the themes to be covered during interviews. Three participants wrote notes in preparation for their consultation interviews and subsequently sent those notes to the Neil. Discussions principally covered the following themes:

- Advice regarding physical activity following diagnosis, treatment, hospitalisation
- Clarity about the need for taking exercise in the context of rehab and ongoing treatment of condition
- Referral by Clinicians to Physical Activity Programmes
- Physical exercise support relevant to respective conditions
- Information and Knowledge
- Current Exercise Levels
- Factors Enabling Physical Activity
- Factors Preventing/Limiting Physical Activity
- What would have made the biggest difference?
- Awareness of others in similar circumstances
- Additional Comments

### **Presentation**

Mindful that this part of the patient consultation is not yet complete and mindful that further consultation will be required with a broader cohort of people living with chronic conditions, this initial summary is presented in a very 'unfinished' format. Feedback on each of the themes listed above is presented either in bullet form or in participant quotes (either from conversation or their respective notes). A more complete consultation report will be prepared in due course. However, in the interests of progressing the planning of the Core Stakeholder Group, information on each of the themes is outlined below.

### **Key Emerging Themes from Consultation to date**

#### *Advice regarding physical activity following diagnosis, treatment, hospitalisation*

- Advice was minimal, more stressing the importance of taking exercise or, in some cases, stressing the importance of building exercise up slowly. But there was little direction on the type or level of physical activity to be taking.

- Physios in hospital were the main source of guidance, with two of the research participants advised on a programme of activity/exercise to follow. The other participants received no advice on a particular schedule of exercise.
- In the case of two interviewees, they ended up taking too much exercise too quickly and had to “learn to listen to my body.”

#### *Clarity about the need for taking exercise*

- All participants were active prior to their diagnosis and all understood the importance of physical activity to health. They also understood its importance in the context of rehab and ongoing treatment of their respective conditions.
- There were mixed experiences in this regard. One person living with MS was advised that exercise would keep flare-ups to a minimum while another interviewee noted, “I was told nothing beyond exercise is good for you.”
- A third interviewee who had suffered heart failure highlighted that, because she had already been physically very active, she felt ignored with regard to exercise while other patients around her (who clearly hadn’t been active prior to their cardiac events) received much more attention:
  - “I felt that the main concern of the medical professional was around your stereotypical heart patient – the older, the ones in the bed, the ones not taking exercise before their cardiac event. And the medics worked with them to change their behaviour. But, if you were active before your illness, it felt like they saw you as fine. There was no guidance around the fact that you may have been doing too much in the build up to your event.”

#### *Referral by Clinicians to Physical Activity Programme*

- None of the consultation participants was referred to any form of physical activity programme in their respective communities. It is important to note that, in the context of the person living with CF, it was pointed out that “people with CF don’t get referred to community rehab or exercise on account of the risk of infection. Those classes don’t exist.”

#### *Physical exercise support relevant to respective conditions*

- All participants referred to the importance of patient representative organisations as the key source of information and support (Irish Heart Foundation, Multiple Sclerosis Ireland, Cystic Fibrosis Ireland, Irish Cancer Society). For example:
  - “I did a Move Smart Programme before Christmas. It’s a programme tailored specially to each individual’s need. You have to fill out a questionnaire and do an interview in advance. It runs in a group of six, all with more or less the same ability levels. I got the link from MSI.”
- The importance of online provision, particularly during Covid lockdown, was also recognised:

- “I follow online workouts from a fitness trainer with the IHF. The service is provided free.”
- “MSI started up physio-led strength and fitness classes online and I joined these.”
- “I looked up the web and have relied on the ICS website a lot. ICS’ advice on how to look after yourself has helped me. They have a very good helpline. I got advice on fitness apps that might be helpful, apps that would be pitched at beginners.”
- A person recovering from Cancer accessed yoga classes through a Cancer Support Group. Interestingly, she learned about the support group from a Community Welfare Officer with whom she was dealing and whose wife was involved with the group.
- One person had been a member of a local gym and had taken up classes in the gym following treatment. However, she quickly found out that the staff there had inadequate training/knowledge relevant to her condition.

### *Information and Knowledge*

- All participants referred to having to find out information for themselves on physical exercise relevant to their conditions and respective capacities. Luckily, all pointed to having the wherewithal to do so.
  - “I had to work out what I was able for myself. I wanted to be active. It was a case of trial and error... I did a lot of research into cardiac rehab. I did classes for heart patients that I found online. I didn’t have a referral pathway. I was left to find it for myself.”
- A couple of participants referred to downloading physical exercise Apps on their phones and following these.
- Only one of the participants was aware of Local Sports Partnerships and only one was aware of Exwell. No reference was made to community-based supervised exercise services similar to Exwell.

### *Current Exercise Levels*

- All taking exercise but most physical activity is self-directed.

### *Factors Enabling Physical Activity*

- “My own initiative and my own ability to search things out for myself.” This comment is reflective of the experience of all five individuals interviewed to date.
- Patient representative organisations – a critical source of information and support. As above, this comment is reflective of the experience of all five individuals interviewed to date.
- Having exercise equipment at home. It is important to note that CFI runs a grant scheme for patients to purchase home equipment or some form of exercise lesson.
- Exercise Apps.

### *Factors Preventing/Limiting Physical Activity*

- “Barriers to exercise include lack of information on what is available to patients from the health sector, fear of taking up an activity in a gym class as how can we be sure it's safe for our condition or that the staff would be trained to deal with us if something went wrong.”
- WIFI in rural communities.
- Injury, frequently caused by not knowing one’s limits.
- Lack of knowledge of what services are out there, including LSPs.
- Some issues specific to individual conditions:
  - “Exercise for people with CF is very important but people need to be very strong. Before the introduction of the CF drugs, I would generally be on IV antibiotics once every three months. It’s like groundhog day. You build up fitness, get sick and then you are back to square 1. To deal with this and to remain committed to exercise, you have to be mentally very strong. Many CF patients fall off the exercise wagon as a result. What’s the point if I’m going to be going backwards all the time?”
  - (In an initial conversation with Irish Coalition for People Living with Obesity): “Pain is the single most important barrier for this cohort. You get treatment for weight loss but because you have been carrying weight for so long, you experience chronic pain and injury. It impacts hugely on your capacity to take exercise.”
- (In a conversation with the Traveller Primary Health Care Programme Team in West Limerick)
  - After diagnosis everybody is given a plan, especially around diet and exercise. The problem in the Traveller community is sticking to the plan. The main problem is that the community isn’t educated enough about the condition and the seriousness of the condition. In the beginning people are frightened by the illness, then they get used to living with it and forget to follow the plan. They progress for a while, think they are better and then stop following the plan. They don’t persevere.”
  - “A lot then just see the medication as their cure. This is part of the education piece.”
  - “Most Travellers with underlying conditions will go to Google for information about the condition and what they should be doing about it.”

### *What would have made the biggest difference to you in your exercise journey?*

- Proper rehab. The patient who had suffered from heart failure, for example, wasn’t offered cardiac rehab. “The ideal for me would have been some form of Cardiac Rehab for about three months, support that would have been tailored to my needs.”
- “An information hub – i.e. what services you can get in your area. If you’ve been affected by a, b or c, this is what is available and relevant to you in your area. Almost like a GPS of services.... Physios and OTs being clear on exercise requirements before you leave hospital. The Physio or the OT is usually your last contact before you leave hospital. At that stage, you are going home to be independent. It would be brilliant if they could advise you on what you need to do to live independently and if they could put you in the direction of services in your local area. Maybe part of this project might be a PACC Compiler. Here’s

what is available for you. Here's the information on cost and location. If you can't drive, here's an alternative, etc. Information is key."

- "What would make the biggest difference? Communication and education for starters. I'd love to see the Sports Partnerships work like the Men's Sheds. Reach out to develop, for example, cycling groups that people with CF could join and maintain fitness. A big fear for people living with CF is that they're not fit enough to join in with people not living with an underlying condition."
- "Mentorship would be really beneficial, someone who'd say to you that this is your exercise session. This is what you are able to do at the moment and I am here to support you. And as we get to know each other, I'll push you a bit to extend yourself a bit further.... It would be great to have a community coach or community mentor at a county level. Let's say they were located in Primary Care. Your GP or specialist could refer you. You would have access to an expert who could train and motivate you and give you a programme to match your needs and abilities. It would be free through the HSE. The service user shouldn't have to pay for it."

*Aware of others with your condition in similar circumstances?*

- "Yes, other heart patients feel there is a disconnect once you are discharged from hospital (or diagnosed as an outpatient). An appointment is made for you to see the doctor but there is no firm follow up on how you practically manage physical activity. You are given brochures about your condition, meds, lifestyle, and told what you can't do, but no details on what you can do and who could help you with that."
- "Fear is a big obstacle for people living with CF. Hospitals will tell parents how important it is for their children living with CF to be active. Physios will tell you to make sure that the whole family is active so that there's no stigma for the one person with CF. But parents often worry too much. There are more healthy people living with CF than in acute situations – on account of the medication. But they are not supported... Lots are doing weights but not so many running. The majority don't exercise properly to get themselves breathless. It's important for CF patients to know their lungs are working hard. Physios don't talk enough about the lungs having to be worked hard."
- "I had a friend with bowel cancer around the same time as me. Like me, she was very active before her diagnosis. After treatment, she didn't know how to start off again. She'd have been grateful for guidance. And once she got back to exercise, she overdid it at the start as well."

### *Additional Comments*

- “One of the challenges for me when dealing with medics is that I present as physically well though I have a chronic condition. They don’t seem to be able to get their heads around me.”
- Two participants highlighted the need for greater focus on activity as a means of preventing the further development of a condition. They felt that there was a tendency particularly among medics to focus on treating symptoms and not enough focus on ongoing preventative action.
- The ongoing difficulty for people with chronic conditions to access health care relevant to their needs, i.e. those without private health insurance or a medical card.
- “It’s not just about the exercise, it’s about having the circle of support around you to support your exercise schedule.”
- “The HSE could do more about educating around disability. It’s not just about people in wheelchairs.”
- “Where are the supports for carers? It’s not easy for people to help those who need help with activity?”
- “You’ve got to remember I am very independent. I can find stuff for myself. But more guidance would be helpful. Some people don’t know where to go to look for help.”
- “The key to supporting people is emphasise local and accessible, supports that people can easily get to, especially if they are not able to drive or if public transport is limited.”

## ANNEXE V: PILOT PROJECT WORKING GROUP TERMS OF REFERENCE

### CONTEXT AND BACKGROUND

Carlow, Waterford and Westmeath Sports Partnerships have initiated a multi-stakeholder collaboration, focused on reducing and removing the barriers that prevent/limit the engagement of people with chronic health conditions in physical activity. The Physical Activity for People with Chronic Conditions Project (PACC) has evolved from a recognition of:

- the personal and therapeutic benefits of physical activity for people experiencing ongoing, chronic health conditions; and
- limited opportunities for people with chronic health conditions in Ireland to access physical activity<sup>30</sup>.

The project is funded under the Dormant Accounts Innovation Fund via Sport Ireland

A core stakeholder group, involving the participating Sports Partnerships, participant representatives, the HSE, representatives from Athlone, Carlow and Waterford Institutes of Technology and a representative of service-providers was established in early 2021 to plan, conceptualise and direct the initiative.

PACC is currently a one-year initiative and is being delivered over two separate but interlinked phases:

- **Phase I** (April – October 2021) has engaged the core stakeholder group in a developmental and consultative process that has informed the selection of three pilot initiatives. The pilot initiatives have been developed following consultation with patients, health and social care professionals, and exercise providers and have been established:
  - to address critical obstacles identified through consultation as impacting negatively on the participation of people with chronic conditions in physical activity; and
  - to test new and integrated approaches to increasing physical activity opportunities for people with chronic conditions.
- **Phase II** (October 2021 – March 2022) involves the design, initial implementation and evaluation of each of the aforementioned pilot initiatives. The initiatives in question seek to:
  - Adapt and extend, in accordance with identified needs, an existing model of exercise provision for people with chronic conditions (the ExWell model);
  - Increase the capacity of exercise providers to provide services to people with chronic conditions by developing a multilevel, accredited training programme for exercise professionals in the area of exercise and chronic illness;

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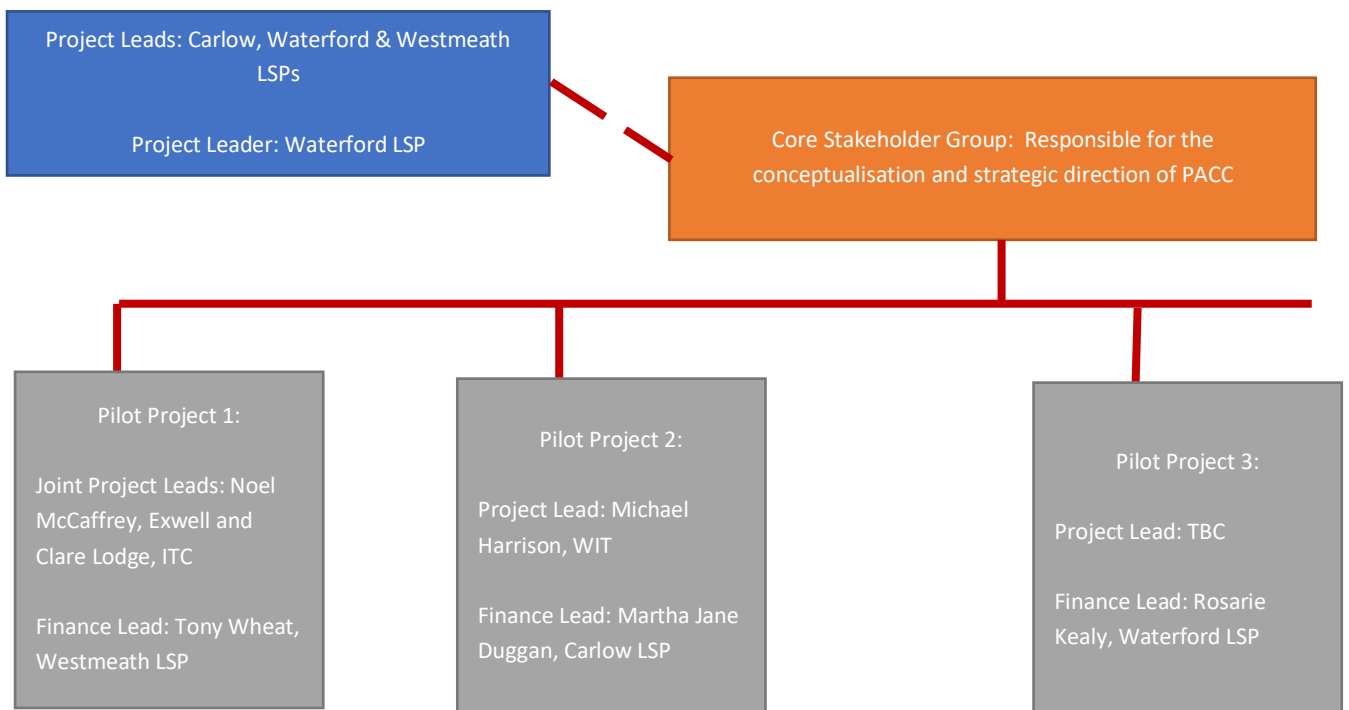
<sup>30</sup> In terms of some or all of the following: accessibility, frequency, affordability, relevance and quality.

- Facilitate a formalised engagement process between healthcare professionals, social prescribers and community-based physical activity providers to increase the participation of individuals living well with chronic conditions within existing community-based physical activity initiatives.

All pilot initiatives are designed and developed to test new ways of working, capture learning and facilitate future replication and scalability in other areas of the country. It is anticipated that additional funding will be secured to enable the pilot projects to be extended and delivered up to December 2022.

### WORKING GROUPS

Each pilot initiative will be designed and overseen by a **PACC Pilot Project Working Group**. Working groups will be convened for the lifetime of each pilot project. A lead agency or agencies has/have been selected to steward each pilot project, while an LSP coordinator has been identified to lead all financial and administrative responsibilities in each project working group. The overall programme, outputs and budget for each pilot will be discussed and approved by the **Core Stakeholder Group**. This arrangement is displayed in the diagram below:





## WORKING GROUP TERMS OF REFERENCE

### *Purpose*

The purpose of these Terms of Reference is to provide a common understanding of the role of the PACC Pilot Project Working Groups in the development and delivery of the aforementioned pilot projects.

### *Vision*

The overarching vision for PACC is to increase opportunities for people with chronic health conditions to access regular, appropriate, supported and high quality physical activity in accordance with their needs and interests, by establishing, planning, implementing and evaluating an innovative project that will:

- respond to the principal obstacles to physical activity that affect people with chronic conditions;
- test and establish sustainable physical activity pathways for people with chronic health conditions;
- enhance collaboration among health, community, academic and the fitness sectors in enabling physical activity for people with chronic conditions
- create an integrated, multidisciplinary model of good practice in respect of physical activity for people with chronic conditions that will have the potential for future replication in multiple locations across the country and in respect of multiple chronic conditions.

The development of each pilot project will be informed by this overarching vision.

### *Principles*

Principles underpinning the Terms of Reference include each of the Pilot Project Working Group members:

- working in a collaborative, cooperative and transparent way, sharing information, opinion and ideas;
- recognising, reflecting and respecting the differing skills, professional contexts, expertise and values of each member of the group;
- working closely with other relevant stakeholders to ensure the best possible input to the working group;
- viewing each member of the pilot project working group as an equal partner;
- recognising and learning from previous and/or current initiatives with similar objectives;
- learning from the development of this initiative and demonstrating a willingness to share the learning with other interest groups.

### *Key responsibilities of the PACC Pilot Project Working Groups*

Members of pilot project working groups will work collaboratively *under the stewardship of their respective group's lead agent* and will have responsibility for:

- contributing knowledge, experience, expertise and other professional resources to the scoping, design and development of the pilot project for which their working group is responsible;
- informing the development of needs-based, outcome-focused pilot interventions;
- participating, as required and as appropriate, in the implementation/delivery of the pilot project for which they are responsible;
- ensuring regular attendance at relevant meetings;
- supporting the design and delivery of monitoring and evaluation procedures for the pilot project for which the group is responsible, and participating in monitoring and evaluation activities as required during the lifetime of the project;
- supporting the lead agent in providing regular reports to the PACC Core Stakeholder Group on pilot project progress and expenditure;
- ensuring that information used through participation in this initiative will not be used for commercial or competitive advantage.

It is important to note that working group membership does not guarantee access to funding. Funding allocation will be determined through the scoping and design of each individual pilot project.

### *Conflict of Interest*

Members of the Pilot Project Working Groups will commit to the highest levels of ethics, transparency and accountability in the fulfilment of their function in progressing the PACC initiative. Members will commit to being honest, fair and independent. They will commit to understanding, declaring and managing conflicts of interest (should they arise) and to protecting and promoting the reputation of all parties involved in PACC.

Should a conflict of interest arise in the operation of the group, the conflicted party(ies) will be asked to remove themselves from the discussion until the remaining group members arrive at what they consider to be a fair, honest and appropriate solution to the issue in question. Should additional support be required to facilitate resolution, matters will be referred to the PACC Core Stakeholder Group for consideration.

### *Time Commitment*

It is difficult to gauge the exact time commitment required pilot project working group members at the point of creating these Terms of Reference. Time commitment will be discussed and agreed

within individual pilot project working groups, based on group members' respective capacity and on the needs of the individual pilots.

*Membership*

To be confirmed