Disability Federation of Ireland, DFI with the Health Service Executive, HSE, the Neurological Alliance of Ireland, NAI.

Joint project to map services provided by voluntary organisations for people living with neurological conditions in the community

Information Webinar

Weds 20 April 2022

10.30 — 11.30

Agenda

Identification of services provided by the voluntary organisations for people living with neurological conditions in the community in each CHO region.

Joint project Disability Federation of Ireland, Neurological Alliance Ireland and the HSE

What is the project about? *NAI & DFI*

Our approach

- **Developing the service descriptors list** *Richard Stables, Joe Condon Stg Group*

- **How you can contribute** *Crowe Consulting*

Why is this project taking place? *Deirdre Scully HSE*

Next Steps *NAI & DFI*

Questions and Answers

Speakers

Identification of services provided by the voluntary organisations for people living with neurological conditions in the community in each CHO region.

Joint project Disability Federation of Ireland, Neurological Alliance Ireland and the HSE

Deirdre Scully — Assistant National Director HSE, Change Planning, Delivery, Disability & Mental Health Services

Richard Stables — Information and Support Manager Headway

Joe Condon — Early Onset Parkinson's Disease

Clodagh O'Brien — Crowe Consulting

Magdalen Rogers — Executive Director NAI

Marie Lynch — Interim Head of Policy DFI

What is the project about?

Identification of services provided by the voluntary organisations for people living with neurological conditions in the community in each CHO region.

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Project Aim

- This project aims to describe and map geographically the existing community services provided by the voluntary sector to people living with neurological conditions from a national perspective.

- It will also seek to identify examples of collaborative best practice between voluntary organisations and the HSE that could be replicated.

Project Goals
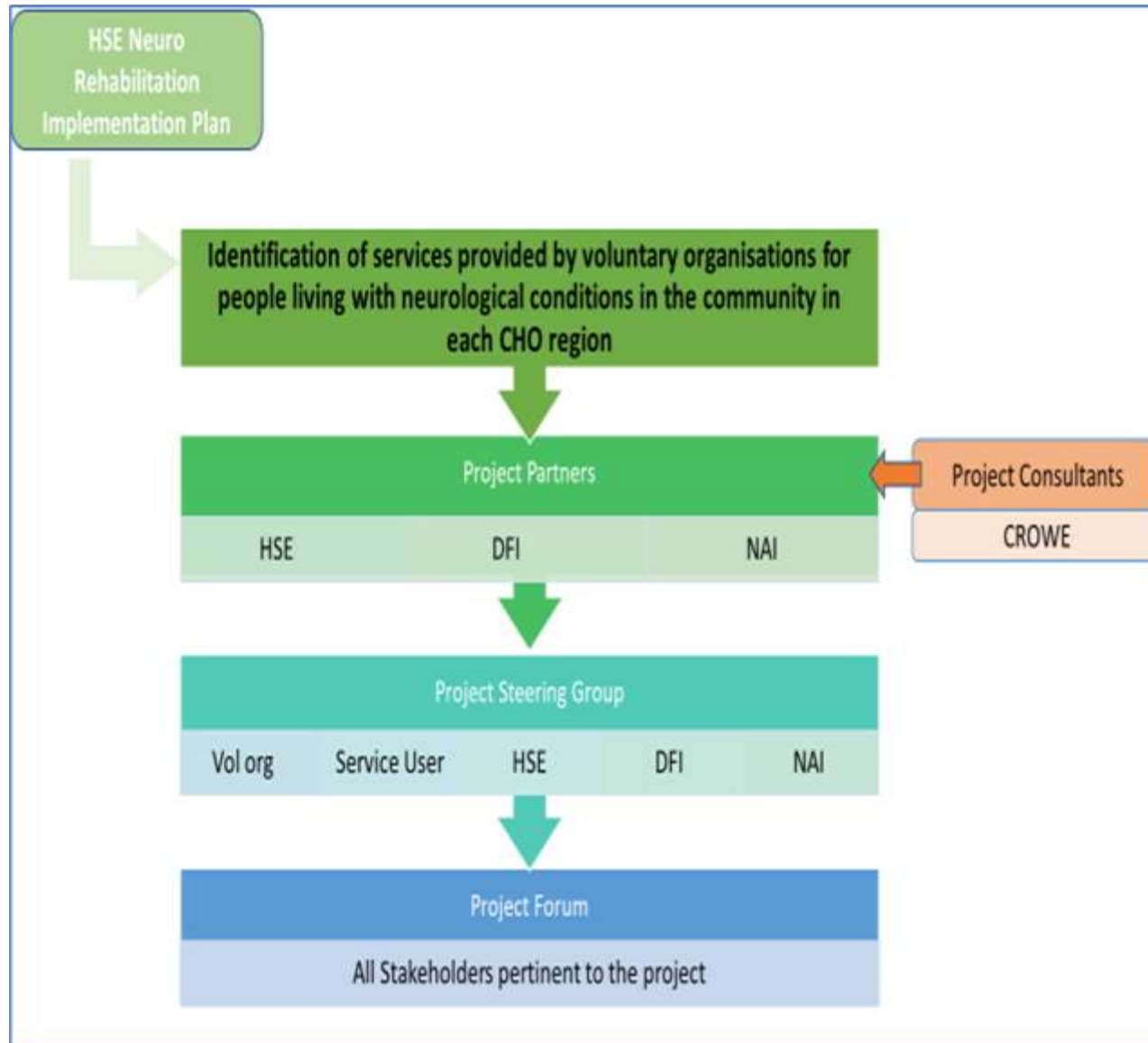
A Solid Foundation for Future Quantitative Mapping

a) Capture all voluntary organisations that provide services to people with neurological conditions

b) Capture the breadth of services

c) Consensus on language used to describe services

Project Structure

Steering Group Membership

Representing	Organisation/ Title	Name
HSE	Prog Manager Neuro-Rehab Clinical Programme	TBC
	SEO	Annette Fitzgibbon
DFI	Policy Advisor DFI	Marie Lynch
NAI	Executive Director NAI	Magdalen Rogers
Member Org	Headway	Richard Stables
	IMNDA	Tracy Hutchin
Patient Rep	EOPD	Joe Condon
	TBC	TBC

Identification of services provided by the voluntary organisations for people living with neurological conditions in the community in each CHO region.

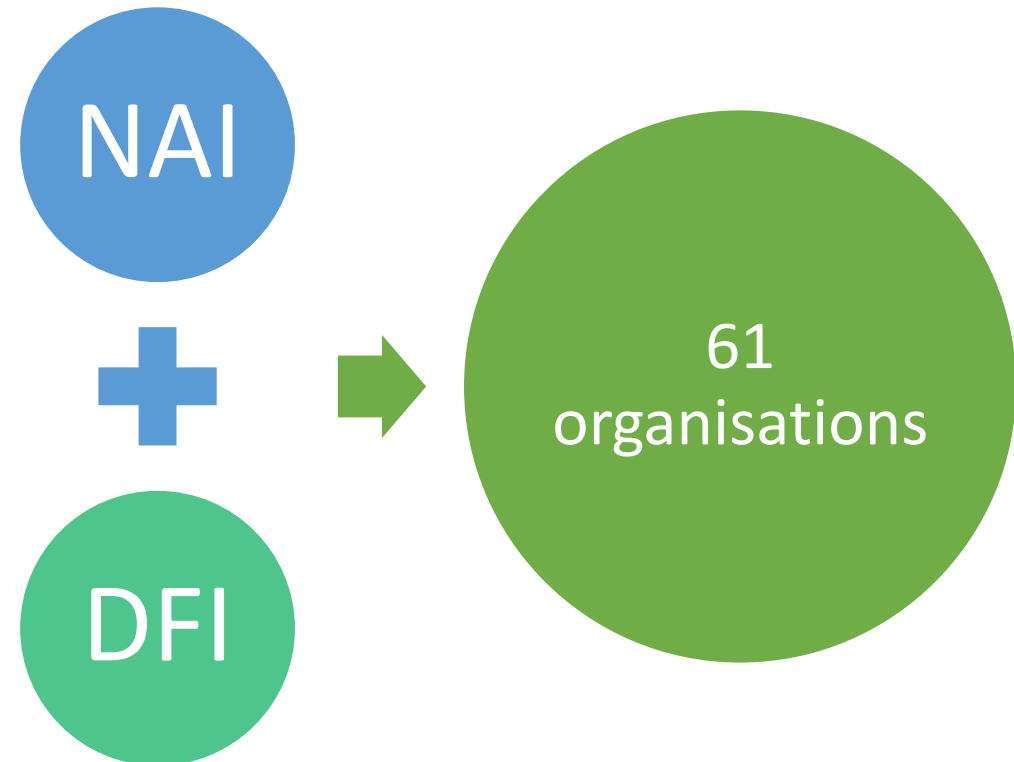Joint project Disability Federation of Ireland, Neurological Alliance Ireland and the HSE

Member Organisations

NAI + DFI → 61 organisations

Identification of services provided by the voluntary organisations for people living with neurological conditions in the community in each CHO region.

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In-scope
✓ Adults 18-65
✓ Community Services provided by voluntary organisations
✓ De-congregated settings
✓ Neurorehabilitation residential facilities

Out-of-scope
✓ Residential care settings for older people
✓ HSE community services
✓ Community based private organisations
✓ Data reports on quantum of services

Overall project timelines

Identification of services provided by the voluntary organisations for people living with neurological conditions in the community in each CHO region.
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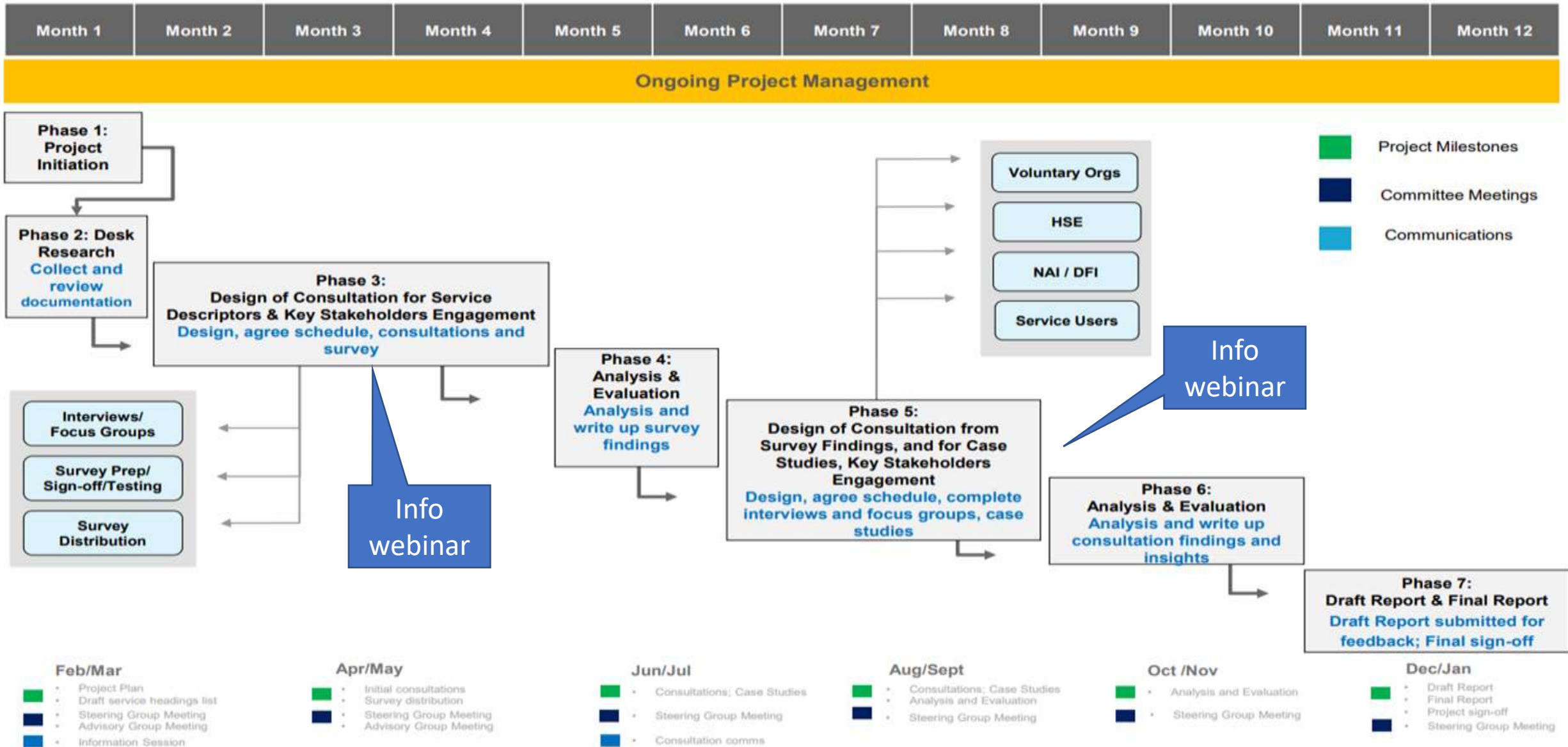
Month 1	Month 2	Month 3	Month 4	Month 5	Month 6	Month 7	Month 8	Month 9	Month 10	Month 11	Month 12

Ongoing Project Management

Phase 1: Project Initiation

Phase 2: Desk Research
Collect and review documentation

Phase 3: Design of Consultation for Service Descriptors & Key Stakeholders Engagement
Design, agree schedule, consultations and survey

Interviews/ Focus Groups

Survey Prep/ Sign-off/Testing

Survey Distribution

Info webinar

Phase 4: Analysis & Evaluation
Analysis and write up survey findings

Phase 5: Design of Consultation from Survey Findings, and for Case Studies, Key Stakeholders Engagement
Design, agree schedule, complete interviews and focus groups, case studies

Voluntary Orgs

HSE

NAI / DFI

Service Users

Info webinar

Phase 6: Analysis & Evaluation
Analysis and write up consultation findings and insights

Phase 7: Draft Report & Final Report
Draft Report submitted for feedback; Final sign-off

Project Milestones

Committee Meetings

Communications

Feb/Mar
- Project Plan
- Draft service headings list
- Steering Group Meeting
- Advisory Group Meeting
- Information Session

Apr/May
- Initial consultations
- Survey distribution
- Steering Group Meeting
- Advisory Group Meeting
- Consultation comms

Jun/Jul
- Consultations; Case Studies
- Steering Group Meeting

Aug/Sept
- Consultations; Case Studies
- Analysis and Evaluation
- Steering Group Meeting

Oct /Nov
- Analysis and Evaluation
- Steering Group Meeting

Dec/Jan
- Draft Report
- Final Report
- Project sign-off
- Steering Group Meeting

Project Goals

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Solid Foundation for Future Quantitative Mapping

a) Capture all organisations that provide services to people with neurological conditions

b) Capture the breadth of services

c) Consensus on language used to describe services

Project Outputs

Identification of services provided by the voluntary organisations for people living with neurological conditions in the community in each CHO region.

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1. Agreed list of service descriptors

2. **Comprehensive list of providers**

3. Case studies representing **collaboration and good practice**

4. **Final report**

Why this project is taking place
Deirdre Scully

- ✓ Link to Neuro-rehabilitation Strategy – Step 10 LIG CHO mapping
- ✓ C & V sector
  - ✓ Common language to describe services
  - ✓ Capturing the range and depth of service provision
  - ✓ Greater recognition of work Template for future mapping
- ✓ *Link to current neuro demonstrator project??*
- ✓ Link to Slainte Care, new RHA and Community Health Care Networks
- ✓ Thanks for your commitment

Our Approach

Richard Stables   *Information and Support Manager Headway*

Joe Condon   *Early Onset Parkinson's Disease*

Why we need you to participate

Our Approach

Crowe Consulting

- The survey will be circulated to a list of contact from whom permission has been given to receive the survey

- The survey will be online

- We will use LimeSurvey software which allows for a range of question types

- A link/"token" will be sent to one recipient per organisation who will need to coordinate a single response

- Completion and submission of the survey will be online

- After the closing date, the survey will be closed and all data will be collated and analysed for inclusion in the report

Our Approach
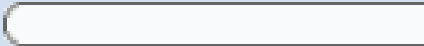
Crowe Consulting
Sample of survey question

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VIA
- Link in chat box
- Email

✓ **Registering to participate in Survey**
   ✓ Key contact person within your organization
   ✓ Consent

✓ Pass the word out to other organisations

✓ Survey commences 9 May

✓ Consultation on Draft findings Aug/Sept

✓ Any more queries contact
   Mags 086 121 6957
   Marie 087 826 3950

- Call or email us
  - **Mags 086 121 6957**
  - **mrogers@nai.ie**
  - **Marie 087 826 3950**
  - **marielynch@disability-federation.ie**

We need your input
- We know that the services that you provide are vital in supporting people living with neurological conditions.
- It is important that your work is captured and recognised.

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Any Questions?

- Discussion Points for Friday 22nd April

- 1. Feedback on Service Descriptors:

- Finalising the list of services and the overarching categories

- 2. Survey Design (including anything we change based on the focus groups/interviews)

- *Crowe may have a clear understanding of survey design but we need to understand it as Project Partners including:*

- -duplication of the same service descriptor under multiple categories (based on how this went down with the focus groups)

- -an "other" option under each category

- -how a single key contact in each organisation collates responses for each CHO (for example do they get a pdf of survey so they can circulate within their org to collate organisation-wide info in advance of data entry)

- 3. Survey Logistics and Timeframes

- -timeframe for survey development/testing/rollout (identifying the key tasks in this and what Project Partners need to do in parallel to support it)

- -feasibility of getting enough orgs on board in this 2 week window

- -organising a one off group "briefing session" for the key contacts from each organisation on how to fill out survey (with Crowe participation)

- (NAI/HSE did this in 2018 mapping and found it extremely helpful to troubleshoot and maximise responses)

- -We have key contacts registering via a registration page on and after 20th April but we need to check with Crowe the following

- (i) does this registration page constitute permission from org (ii) data sharing perspective: are we in NAI/DFI in a position to remind/encourage those who have not completed surveys to do so

General queries

- Queries on Home from Home?
- Query about what home from home services are versus step down care?
- Query on 5.m. Day services – accessibility supports. Includes both communication and physical accessibility?
- Where is independence? Result not service. Similarly, community inclusion questioned – outcome or service? Part of PCP?
- Does there need to be a separate service for acquired RT and Day Services?? No pot though so not funded service
- What about Family support service or Community Resource that includes both family and individual?? Would end up ticking under 9. And any of the other 9 categories that the individual avails of. Agreed that that was ok.
- Advocacy on national policy issues raised and agreed that as it wasn't a direct service it was ok to exclude.
- Conversation about including definitions for categories and agreed that better to

category.

- Questions around the inclusion of a glossary of terms, like the HSE one, e.g. indicating what are day services i.e. day services might be 'new directions' funded day services

- Query if survey queries will be directed to a dedicated person?

- Discussion around drop down boxes for notes being available on the survey?

- Queries research and PPI (patient participation involvement) at the universities. Noted that this is a type of service because it offers the facility for 'patient voice' i.e. research with a patient rather than on a patient

- Query about what is meant by a specialist nurse specifically i.e. what kinds of specialist nursing?