HSE National Patient and Service User Forum

TERMS OF REFERENCE

Rationale

The HSE National Patient and Service User Forum is the HSE’s primary consultative body for involving partners in the work of the Chief Executive and the National Directorates.

Objectives

The objectives of the HSE National Patient & Service User Forum are:

* to be an open, inclusive network of individuals representing the public and patient and service user community
* to advance the ‘partnership in action’ agenda, detailed in the ‘vision for partnership’ document (June 2022)
* to provide national health service partners with a mechanism for engaging with each other and with a broad range of patient, service user and public partners, including representatives from organisations and community groups
* to advise on partnership approaches around key pieces of work within the health service, including aspects of Slaintecare, national strategy implementation, major projects work
* to support the HSE PSUE to publicise the partnership approach to health service management
* to advocate for the inclusion of patient, service user and public partner perspectives across the health system, including the design, implementation and evaluation of strategies, plans, programmes, projects and governance arrangements

Membership

The membership of the Forum comprises of a mix of individual patients and service users; families, carers; and voluntary, community or advocacy organisations.

The Forum invites organisation members to act as representatives of their organisations, and not in their own individual capacity. To this end, they should seek to liaise with their organisation members with lived experience to provide their organisation’s position on the Forum’s priority areas.

The Forum welcomes individual members who:

* have an interest in the ‘partnership in action’ agenda, as detailed in the ‘vision for partnership’ document\* (June 2022)
* are able to apply their own individual lived experience more generally to the wider public or patient and service user community experience
* adhere to the code of conduct, as detailed in this terms of reference

\*PLEASE NOTE: While we recognise that many partners come to partnership as a result of a personal (often negative) experience with the health system, the Forum is not a place for resolving individual issues or complaints. The Forum is focused on embedding partnership approaches across the health service, and our activities align with agreed priority areas.

The Forum will share public information (with the support of the PSUE office) to ensure representation from a broad range of individuals and organisations representing different conditions and different communities.

If necessary, the number of Forum members will be managed by the co-chairs to ensure that meetings remain effective.

Responsibilities

The Forum members agree to undertake the following responsibilities:

* To develop strategies designed to achieve the objectives of the Forum
* To develop an annual work plan which is reflective of these terms of reference, and of the priorities of both the Forum members and the HSE
* To ensure that necessary and appropriate secretariat supports are agreed with the HSE
* To ensure effective communication between the Forum and the HSE at national level
* To nominate, on request, members to represent the Forum on consultation/reference groups at a national level within the HSE
* To produce an annual summary of the activities of the Forum

Representation

The Forum is often asked to identify patient or service user or public partners to engage in partnership activities or co-production processes.

If necessary, the number of requests will be managed by the co-chairs to ensure that partners are selected for opportunities which align with the Forum’s identified priority areas.

To identify partners, the Patient and Service User Experience (PSUE) office will:

* circulate a flyer containing the details of the partner role to Forum members
* request interested Forum members to complete an expression of interest template\* (see appendices)
* review expressions of interest, together with the co-chairs and health service staff members involved in making the original request for public partners
* notify those expressing interest of the outcome of the process
* add the nominated partner to the database of partner roles

\*Please note that in submitting an expression of interest to be nominated as a public partner you are agreeing to your name and contact details to be displayed on the database of partner roles. The database is publicly available.

Nominated partners should update in writing the database of partner roles with the dates of meetings and with a short note of the decisions taken. Where appropriate, nominated partners may be called on to verbally report on their activity during meetings of the Forum. A note of any important points raised should be made by the HSE Patient and Service User Experience Office members on the database of partnership roles.

Communication

To ensure good governance, the co-chairs of the Forum are solely responsible for all written communication (including documentation) issued on behalf of the Forum (i.e. signed ‘The HSE National Patient and Service User Forum’).

Members interested in having the Forum collectively submit a written communication on a specific issue should raise their request during one of the regular meetings. The co-chairs will then bring this request to the attention of the Forum, which will consider and decide on these requests on a case-by-case basis.

Any member of the Forum identified as issuing a written communication or document purported on behalf of the Forum without the express prior agreement of the Forum will be removed from the Forum.

PLEASE NOTE: This provision in no way precludes Forum members from issuing their own individual/personal communications in their own name or in the name of their voluntary, community or advocacy organisation or group. This provision is in place to ensure that individual members of the Forum do not seek to act on behalf of the Forum without the majority consent of Forum members.

Chairperson

The Forum will elect two representatives from the Forum membership to co-chair the Forum. At least one chair should be a representative of a patient or service user or voluntary, community or advocacy organisation. Where possible, this ‘organisation’ chair should take the primary role in supporting the drafting of documents for the Forum.

The term of office of the two co-chairs shall be two years. The co-chairs may be automatically renewed (by an informal vote of the forum members attending the first annual meeting) for a further two years after the end of the first term.

A formal balloted vote shall be held at least every four years. This is coordinated by the PSUE office.

The co-chairs currently give their time on a voluntary basis. In the future it would be envisaged that the chair with lived experience would receive an ‘involvement payment’ in line with the draft Department of Health Public Involvement Partners (PIP) policy.

The co-chairs will:

* organise and chair meetings of the Forum
* coordinate Forum activities with the HSE PSUE office
* represent the Forum at conference, events, meetings, workshops
* draft emails, letters, requests, positions on behalf of the Forum

Forum administration

The Forum will nominate (by an informal vote of the forum members attending the first annual meeting) two co-administrators.

The term of office of the administrators shall be two years. The administrators may be automatically renewed for a further two years after the end of the first term.

The co-administrators give their time on a voluntary basis.

The co-administrators will:

* minute the meetings of the Forum
* support the strategic planning work of the co-chairs
* join meetings with HSE staff at the request/invitation of the co-chairs

The forum administration will aim to grow a pool of individuals who can step in for chairs when they are not available, or who can put themselves up for election to the role of chair in the future.

Observers

The Forum is all about partnership, and we incorporate this into our meetings. A list of approved observers will be maintained, and these observers will receive invites to Forum meetings.

Meetings

The meetings of the Forum will be held on a bi-monthly basis or more frequently as agreed by the members.

The items for consideration by the Forum members will be circulated no less than one week in advance of each meeting. The minutes from the previous Forum meetings should be circulated at this time.

Code of conduct

The Members of the Forum should:

* support the ‘partnership in action’ agenda, as detailed in the ‘vision for partnership’ document (June 2022)
* seek to represent the shared positions and approaches, as agreed by the Forum
* raise any partnership issues and concerns with the co-chairs, as a first course of action
* live the values of partnership in their interactions with HSE staff (respect, equality, understanding, empathy, transparency etc)
* adhere to these terms of reference

Forum members who do not adhere to these terms of reference will be asked to leave the Forum and will be removed from the Forum mailing list.

Conflict of interest

It is imperative that individuals serving on the forum prioritize the best interests of patients and service users above personal or professional affiliations. Any potential conflicts of interest, whether financial, familial, or otherwise, must be promptly disclosed to ensure unbiased decision-making and uphold the credibility of the forum.

Members are asked to disclose any potential conflicts when completing their membership form, and at the start of each meeting the chairs will remind members to declare any new conflicts, the secretariat should then update the member’s conflict of interest register as appropriate.

Review of the terms of reference

The operation of the Forum, to include a review of these terms of reference, will take place on a bi-annual basis.

Document history:

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| --- | --- |
| Drafted | 2015 |
| - | A record of revisions made during this time was not recorded. |
| Revised | August 2021 |
| Revised | December 2023 / January & February 2024 |

APPENDIX 1

Forum meetings in 2024

|  |  |  |
| --- | --- | --- |
| Jan | 11th, 1030-12 | Completed |
| Feb | 15th, 1030-1130am | Completed |
| Mar | 14th, 1030-1130am | Completed (Health Regions) |
| Apr | 18th, 1030-1130am | Completed (Partnership mechanisms) |
| May | 15th, 1030-1130am – in-person |  |
| Jun | 13th, 1030-1130am – in-person |  |
| Jul | 11th, 1030-1130am |  |
| Aug | No meeting |  |
| Sept | 12th, 1030-1130am |  |
| Oct | 10th, 1030-1130am |  |
| Nov | 14th, 1030-1130am |  |
| Dec | 12th, 1030-1130am |  |

APPENDIX 2

Forum priority areas in 2024

* HEALTH REGIONS: As foreseen by Slaintecare, the establishment of six health regions is currently underway. It is important that partnership is embedded across the regions from the start. Partnership offices need to be created within the management structures, and they need to be resourced with expert staff and with adequate budgets to carry out a programme of activity.
* DIGITAL HEALTH: As foreseen by Slaintecare, the creation of a digitally enabled health service is being advanced. It is important that partners inform the direction of Departmental and HSE roadmaps and implementation plans. Programme and project teams need to be engaging with a cross-section of the community to ensure that the solutions identified meet the needs, expectations and preferences of the end users – patients, service users, members of the public, clinical and non-clinical staff.
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APPENDIX 3

Forum members in 2024 – membership form

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| --- |
| Name: |
| Type of forum member: |
| * Patient or service user with lived experience |
| * Family member or carer of patient or service user |
| * Voluntary, community or advocacy organisation   + Please share the name of your organisation   + Please share your position within your organisation |
| Why are you interested in joining the HSE NPSU Forum? |
| What county do you live in? |
| What county do you mainly access health and social care services in? (provide one or more counties if applicable) |
| Do you have a particular interest in certain strategies, programmes, policies, projects within the health service? |
| If you already have experience of partnership, please share some information. |
| Would you like to join one of our working groups?   1. Conference 2. Policy 3. Communications 4. Membership |
| Do you have any conflict of interests to disclose? |
| Please share the email address you wish the HSE Patient and Service User Experience Office and the HSE National Patient and Service User Forum to contact you on: |
| Do you consent to share your contact details with the HSE Patient and Service User Experience Office? |
| Do you consent to share your contact details with the other HSE Patient and Service User Forum members? |
| Do you consent to share your contact details publicly in HSE National Patient and Service User Forum public information material (the HSE NPSU Forum webpage and any the HSE NPSU documentation)? |

Forum members in 2024 – membership database (public)

|  |  |  |  |
| --- | --- | --- | --- |
| NAME | TYPE OF FORUM MEMBER | CONTACT DETAILS | CONSENT TO SHARE PUBLICLY |
| Anne Lawlor  (co-chair) | Family member, Voluntary, community or advocacy organisation |  |  |
| Laura Kavanagh (co-chair) | Voluntary, community or advocacy organisation | [lkavanagh@ipposi.ie](mailto:lkavanagh@ipposi.ie) | Yes |
| xx  (secretary) |  |  |  |
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APPENDIX 4

Forum partnership roles in 2023/24

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| --- | --- | --- | --- | --- | --- |
| Partner role | Term | Description | Rolling list of issues | Forum reps | Status |
| Just Culture Working Group | 2 year term Every two months | The overall purpose of the Just Culture Working Group is to agree a strategic plan to promote a Just Culture in the HSE and will champion, advance and support its implementation. |  | Joan Johnston?  Sorcha Boyle? |  |
| Better Together Implementation Working Group | Fortnightly |  |  | Anne Lawlor  Laura Kavanagh  Christine Fenton  Kara Madden  ? |  |
| Health Regions Steering Group | Monthly |  |  | Kara Madden (advocate)  1 other | Stood down |
| Health Regions Implementation Group | Monthly |  |  | Christine Fenton (advocate)  Formerly Anne Lawlor & Laura Kavanagh |  |
| Health Regions Integrated Service Delivery Workstream Group |  |  |  | Christine Fenton  Sorcha Boyle  Lisa Fenwick  Anne Duffy |  |
| Digital Health Reference Advisory Group | Monthly |  |  | Liam O’Sullivan (Carers Alliance)  Laura Kavanagh  (IPPOSI) |  |
| Slaintecare Implementation Framework 2024-27 | Nov 2023 Once off engagement |  |  | All forum |  |
| Mobile Patient Health App | Monthly |  |  | Laura Kavanagh  Aileen Killeen  Vicky Harris  Bibiana Savin  Mary Brigid O’Reilly  Dawn O’Haire  Eamon McPartlin  Eilis ni chaithnia  Helen Fitzgerald |  |
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APPENDIX 5

Forum expression of interest template

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| --- | --- |
| Name of forum member: |  |
| Professional or personal interest in role: (1-2 sentences) |  |
| Experience of (or expertise in) to topic area: (3-4 lines) |  |
| Confirm availability to attend at times provided: |  |
| Confirm commitment to report back to forum: |  |
| Confirm consent to share your name on database of involvement roles: |  |

Please note that in submitting an expression of interest to be nominated as a public partner you may agree to share your name and contact details on the database of partner roles. The database is publicly available.

APPENDIX 6

Forum requirements when considering partner role requests

* The request should be written in plain English, with no acronyms.
* The request should clearly state from which team in which location, attached to which department, the request is being made.
* The request should include a description of the type of partner being requested e.g. voluntary, community or advocacy organisation representative, individual patient or service user, lay person etc. Ideally, the request should make provision for the inclusion of a range of partner experience.
* The request should include details of any pre-scheduled meeting dates and times to allow partners to assess their own availability before expressing interest.
* The request must be received in writing (using the flyer template) at least eight weeks prior to the start of the partnership activity (to allow for internal expression of interest process).
* The request should be ideally co-designed with the partner community to ensure that the role is suitable.
* The request should seek to partner with at least two public, patient, service user partners, and where possible, provision should be made to appoint two alternates in case of illness or absence.
* The request should include an opportunity for partners to be briefed, updated, onboarded around the details of the relevant programme of work.
* The request should provide partners with the same level of information and documentation as is being provided to other members of the committee, working group, other.
* The request should detail how partner input will be considered in the decision-making process.
* The request should detail the process for how partners will be able to feedback on their experience at the end of the activity.

APPENDIX 7

Observers of the Forum

* The Patient and Service User Experience Office, national
* The Patient and Service User Experience Leads, hospital and community
* The HSE Senior Management Team
* The HSE Board
* The HSE Health Regions Team

APPENDIX 8

Experience of Partner Role Feedback (patient, service user)

1. How would you rate your experience of your partner role? (1 being poor, 3 being ok, 5 being excellent)
2. What went well?
3. What didn’t go so well?
4. What could have made your experience better?
5. What would you like to see in terms of developing the partnership voice in this space?

APPENDIX 9

Experience of Partner Role Feedback (provider)

1. How would you rate your experience of involving public partner in your work? (1 being poor, 3 being ok, 5 being excellent)
2. What went well?
3. What didn’t go so well?
4. What could have made your experience better?
5. What would you like to see in terms of developing the partnership voice in this space?