



Appendix L: My Involvement Profile Template

Patient & Public Involvement and Engagement (PPIE) Group at [Name of Site]

Thank you for your involvement in Pakistan's first-ever PPIE group! The primary purpose of this group is to make research conducted at [name of site] more relevant and meaningful for the people in Pakistan. We will review ongoing research and discuss how they can be improved.

The aim of completing this document together with us, the coordinators, is so that we can better understand your background and experience, your preferences, your requirements for support as well as your expectations of the project. This allows us to better understand members of the PPIE group and determine how we can align our objectives to reach our desired outcomes. This exercise will help us facilitate group discussions efficiently and ensure equal participation.

All information provided will be kept confidential and will not be shared with other members of the group. It will be stored in a password-protected folder that can only be accessed by the coordinators of the PPIE project and the document will be permanently deleted one year after you leave the group (or earlier upon your request).

Part 1 - Personal Information

1. Contact details

Name:

Address:

Telephone number:

Email:

Social media:

- Instagram:
- X/Bluesky:
- LinkedIn:

Year I was born:

Sex: Male / Female / Intersex / I prefer not to answer

My highest level of educational attainment:

- Below Primary
- Primary (Class 1-5 & Age 6-10)
- Middle (Class 6-8 & Age 11-13)
- Matric (Class 9-10 & Age 14-15)
- Intermediate
- Graduate
- Masters & Above
- Diploma / Certificate
- Other (please specify):
- I prefer not to answer

My current work status:

- Working (including full and part-time work, self-employment, unpaid family helpers)
- Seeking work
- Student (including part and full-time student)
- House Keeping
- Other (please specify - e.g. retired, volunteer, on parental or short-term leave, receiving benefits):
- Prefer not to answer

My mother tongue:

- Urdu
- Punjabi
- Sindhi
- Pushto
- Balochi
- Kashmiri
- Saraiki
- Hindko
- Brahvi
- Other (please specify):
- I prefer not to answer

Name of emergency contact:

Relationship of emergency contact:

Telephone number of emergency contact:

2. Preferred communication method

- WhatsApp, SMS, email, voice notes, phone calls

3. Required format of information

- Google Document (requires a Gmail account)
- Word Document (requires Microsoft)
- PDF

4. Preferred language

Spoken: English / Urdu / Other

Written: English / Urdu / Other

5. Why I want to take part in this involvement activity or PPIE group

6. Other involvement and research activities I have done

a) Involvement

I have taken part in involvement activities for the following organisations:

The area of involvement is/was:

The types of involvement activities I have done include:

b) Research studies and clinical trials

I or my family member have been part of research studies and clinical trials: Yes / No

My general attitude towards research and clinical trials is:

7. My relevant skills

Skills

-

As a result of these skills, I think I can contribute to the PPIE project in the following ways:

8. My paid and unpaid work experience

Current work

-

Experience

-

I have worked for pay in a healthcare profession: Yes / No

9. Education, training and other interests

Degrees, Diplomas & Certificates

-

Interests (personal and professional)

-

10. Social media and marketing

All social media posts and marketing materials (e.g. website, leaflets) containing any information about you will always be shared with you for review prior to publishing. Saying 'Yes' to any of these questions does not mean that we will publish anything publicly without your permission.

Generally, I am comfortable with the use of my name as part of social media posts and marketing materials (e.g. website, leaflets)

- Yes / No

Generally, I am comfortable with my social media accounts being tagged in social media posts

- Yes / No

Generally, I am comfortable with the use of pictures and videos of me as part of social media posts and marketing materials (e.g. website, leaflets)

- Yes / No

Part 2 - Access and Support Requirements

This section explains my access and support requirements.

1. Format of papers and documents

I need the following formats: Large font / Small font

I need materials in advance: Yes / No

If Yes, how many days in advance:

Please send documents to me in the following way: Hard copies / Soft copies on email/WhatsApp

If this is a remote activity I prefer to use: Platform/Tool: Zoom / Teams / Skype / WhatsApp
Device: Phone / Laptop

2. I need these access arrangements

For in-person events:

- Mobility
- Breaks (e.g. prayer, smoking, rest)
- WiFi

For remote events:

- Devices

3. I will be bringing support with me

Yes / No

If Yes, the name of my assistant is:

4. I need support to be provided on the day

Yes / No

If Yes, please specify:

5. I am available at these times and days

Weekdays / Weekends

Mornings / Afternoons / Evenings

6. I or the person attending with me have some dietary requirements

Yes / No

If Yes, please specify:

7. I am clear on the amount, process and reasons for reimbursement as part of this PPIE project

Yes / No

Part 3 - Expectations

This section is about my expectations regarding the PPIE group

1. Role

Member of the public / Patient / Patient's attendant

2. My impression of PPIE is:

3. My expectations from this PPIE group are:

4. In my opinion, patients and the public can be involved in research:

Yes / No

If Yes, how and where can patients and the public be involved:

5. I have concerns about the involvement of patients/public in research:

Yes / No

If Yes, please specify:

6. I have concerns about my involvement in the PPIE group:

Yes / No

If Yes, please specify:

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If you have any further questions, please contact us via:

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