Patients and Public Involvement

Patient and Public Involvement is crucial to UKEPSS and we will provide a **summary section** for each disorder under surveillance

Patients and public have been involved and will continue to **influence all aspects of the Service** including:

- design of the research,
- management of the research (e.g. steering/advisory group),
- developing participant information resources,
- undertaking/analysing the research (e.g. member of the research team),
- contributing to the reporting of the study report,
- dissemination of research findings.

The UKEPSS programme benefited from the **involvement of lay members with direct experience** of early pregnancy losses. We will welcome volunteers to provide ongoing comments and advice.

The Patient and Public involvement discussions thus far have highlighted the need for:

a) **active user involvement** throughout the lifetime of the project

b) involvement of the **partners of women**

c) the importance of involving **specialist patient support groups**

d) **wider dissemination** of the findings to users

Women and their partners, chosen to reflect a wide range of social and ethnic backgrounds, views and experiences, will be invited to participate in future qualitative studies. The qualitative element of UKEPSS research will be managed by researchers with extensive experience of working with patients and public and they, along with the patient representatives, will determine for each project what degree and type of patient or public involvement is best.

Research findings will be disseminated at the annual meeting of the AEPU which is attended by patients and health care professionals. It has a patient forum where women affected by early pregnancy issues talk to EPU conference delegates, and the UKEPSS team will actively engage in this forum.

Thus **patient and public involvement** will be **embedded into the UKEPSS programme** both at the global strategic level and at the level of each individual study

For information about early pregnancy or to find an Early Pregnancy Unit near you please go the **Association of Early Pregnancy Units website (http://www.earlypregnancy.org.uk/)**

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