

LAY CONTRIBUTIONS TO A SEXUAL HEALTH SURVEY OF SUBSTANCE MISUSING WOMEN

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OUTLINE

INTRODUCING THE STUDY:

Partners

Background to the study

Basic study design

LAY INVOLVEMENT:

Engaging 'experts by experience'

Lay contributions

Impact of lay involvement

INTRODUCING THE STUDY

PARTNERS AND FUNDING

- Dr. Anthony Glasper, Consultant Psychiatrist SMS Hastings
- Dr. Harish Patel GUM Consultant, Hastings
- Crime Reduction Initiative/ Addaction
- Seaview Health and Wellbeing Centre
- GPSI- Dr. Hannah Hughes
- PCT – Dr. Dulcie McBride, Dr. John Vesely
- Police Outreach Drugs Worker- Bryan Graves
- Research fellow, research assistant and 2 lay people appointed after funding secured

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BACKGROUND

Injecting drug users and sex workers are target populations for sexual health and HIV prevention and Treatment¹

BACKGROUND

- high rates of sex work (defined as exchange of sex for money or drugs) among injecting and non-injecting female substance misusers ^{2,3,4}
- low uptake of cervical 'smear' testing among opiate-dependent women attending a methadone-maintenance programme ⁵
- low rates of condom use among sexually active SMW -regular use by 21% of opiate dependent women ⁴, use in last month by 24% of women in drug treatment ²
- high rates of STIs -75% of women in drug treatment programmes had had at least 1 STI ², almost half of women attending a methadone-maintenance programme had had at least 1 STI ⁶
- low uptake of regular contraception -60% of sexually active women attending a methadone maintenance programme used no form of contraception ⁶
- high rates of unwanted pregnancy and associated health and fiscal implications for mother and child ⁷ 50% of women attending a methadone maintenance programme reported a previous unwanted pregnancy ⁶
- negative perceptions of 'family planning' services ⁶
- negative perceptions of drug misusing women by health and social care providers ⁷

BACKGROUND

- Paucity of research
- Methodological limitations?
- Ethical concerns?

Research design and environment as protective ⁸

BACKGROUND

Growth in public involvement

Exploring Impact⁹

- Improving the consent process
- Helping researchers to develop ethically
- acceptable research
- Developing relevant outcome measures
- Increasing recruitment and access

Public involvement in research is founded on the core principle that people who are affected by research have a right to have a say in what and how research is undertaken⁹

STUDY AIMS

- To identify sexual health risks and morbidities, and sexual health service use among substance-misusing women
 - type and frequency of sexual health risks and morbidities
 - levels of sexual health service use
 - enablers and barriers to that use among SMW
 - user preferences concerning sexual health service delivery
- To determine the impact of service user collaboration on research methodology
- To define a model for optimal sexual healthcare delivery for SMW

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Stage 1

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Stage 2

STUDY DESIGN

Population: Women aged 18+ in Hastings & Rother area currently misusing substances

- 'Data on type and frequency of sexual health risks and service use will be collected by structured questionnaire'

DEFINITIONS

- **Substance misuse** is defined as the misuse of illegal or illicit drug taking which leads a person to experience social, psychological, physical or legal problems related to intoxication or regular excessive consumption and/or dependence. ¹⁰
- **Sexual health** in this context refers to prevention and treatment of sexually transmitted infections and unwanted pregnancy, cervical screening, contraception, and antenatal and postnatal health.

ENGAGING
'EXPERTS BY EXPERIENCE'

LAY INVOLVEMENT

JOB DESCRIPTION

Things you might be asked to do as volunteer user researcher:

- Attend meetings every 2 – 4 weeks (with about 6 other people there)
- Read forms, questionnaires and short reports and tell us how to improve them
- Help us to think of ways to find substance-misusing women and ask them questions
- Help us to think of important questions to ask substance-misusing women
- Help us to write down what sexual health services should be like for substance-misusing women
- Make notes about your experiences of working on this research project

Skills and commitments you would need to do the research voluntary work:

- Be a woman who has misused substances
- Be at a stable stage in your substance-misuse treatment
- Be able to work as part of a team
- Be able to get involved for at least 2 months
- Have a friendly and approachable manner
- Be confident to give your opinions
- Be a good listener
- Have a reasonable level of writing and reading ability (eg. the Sun newspaper)
- Have a level of drug use which will not affect attending or taking part in meetings

LAY INVOLVEMENT NEGOTIATION

- Are you happy for me to disclose to others your name and involvement in this project?
- How much time do you have to spare?
- Possibility of continuing or not
- Payment and reimbursement situation
- Attending meetings with other users, and clinicians
- How can we contact you?
- Is it OK to leave messages?
- Sensitive nature of topic
- Right to withdraw at any stage
- Offer of research training
- Availability for certain days

LAY INVOLVEMENT RECRUITMENT

- 5 potential lay researchers, were identified by staff and keen to discuss involvement with the research team
- 2 unable to maintain communication
- 1 circumstance change
- 2 attended all meetings for one year
- 1 still involved

LAY CONTRIBUTIONS

LAY CONTRIBUTIONS

- Who should be eligible for the study
- Questionnaire design
- How to access our population and where to collect data
- Advertisement
- How to encourage women to take part
- Informed consent- participant information sheets and capacity to consent
- What support women may need during and after

QUESTIONNAIRE DESIGN

- What questions to ask
- What questions to avoid
- Ensuring questions are relevant
- Terminology
- Item construction

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- What questions to ask GP gender, services, exchange of sex, condoms for oral sex
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- What questions to ask GP gender, services, exchange of sex, condoms for oral sex
- What questions to avoid Stillbirth, looked after children
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QUESTIONNAIRE DESIGN

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- Ensuring questions are relevant Number of partners in last 90 days
- Terminology Colloquialisms for oral sex
- Item construction

HOW AND WHERE TO COLLECT DATA

- Homes **x**
- Soup kitchens **x**
- Snowball sampling and peer researching **x**

Ensuring a 'safe space' during and after participation

RECRUITMENT AND DATA COLLECTION

Recruitment sites:

- CRI/SMS Hastings
- 'Seaview' Health and Wellbeing Centre, St. Leonard's
- Hastings Police Station Outreach worker room

ADVERTISEMENT POSTER

Are you a woman with a substance misuse problem?

Complete a 'Women's Health Study' questionnaire and receive a
£5 Body Shop or Boots voucher

What is the Women's Health Study?

It's a research project to find out the best way to provide sexual health services to women with substance misuse issues. It's being led by the University of Brighton and Sussex Partnership NHS Foundation Trust with support from SMS, CRI, Seaview and ex-service users.

Who do you want to take part?

All women (aged 18+) staying in Hastings & Rother who have a substance misuse problem.
We offer a £5 Body Shop or Boots voucher for your time.

Where would I have to go to do a questionnaire?

Come to CRI, SMS, or Seaview and just say you want to do a Women's Health Study questionnaire.
You don't need to go there regularly and you won't be expected to start either.

What does taking part involve?

Spend 15-20 minutes filling out a questionnaire about your sexual health and use of services (with support from a researcher or member of staff if you like). Don't put your name on the questionnaire and place it in a sealed envelope so only the university researchers will see the answers.

What would happen to my answers?

They would be looked at only by researchers at University of Brighton. Your name won't go on the questionnaire so that no-one can trace your answers back to you anyway.

How do I find out more?

Pick up a leaflet from CRI, SMS or Seaview, speak to CRI or SMS staff or call Leanne on 07934 627348.

ADVERTISEMENT SITES

Public toilets

Counselling services

Alcohol misuse services

GP surgeries

St. John's Ambulance

WRVS

Police station

Supported housing

Genito-urinary medicine clinic

PARTICIPANT INFORMATION SHEET

INFORMATION ABOUT THE 'WOMEN'S HEALTH STUDY' QUESTIONNAIRE

What is the Women's Health Study?

It's a research project to design sexual health services for substance-misusing women, though we can't promise services will change as a result. It's being led by University of Brighton and Sussex Partnership NHS Foundation Trust who will store and look at the answers.

Will my filling out a questionnaire be kept confidential?

You don't have to give us your name or contact details. Your questionnaire will be stored without your name on it in a locked filing cabinet and in a computer database at University of Brighton for 10 years. If you have assistance with completing the questionnaire and report to that person something which indicates a serious risk of harm to yourself or someone you know, we will break confidentiality at that time.

What would taking part involve?

If you are a woman aged 18+ in the Hastings & Rother area and you have a substance misuse problem we would like you to take part.

1. Drop in or arrange to do a 20 minute questionnaire in a private room at CRI, SMS, Seaview or Hastings Police Station.
2. DON'T put your name anywhere on the questionnaire
3. Fill out the questionnaire on your own, or with a researcher or care co-ordinator if you prefer. We will give you a £5 Body Shop or Boots voucher to thank you for taking part.

What will happen to the study findings?

Your name will *not* be included in any reports or publications. Free reports of the study findings will be available on request at CRI/ SMS. The findings will also be published in health care journals and conferences and you can request a copy of these via CRI/SMS.

Who is organising and funding the research?

This study is funded by the National Institute for Health Research and is being sponsored by the Sussex Research Consortium. It has been approved by Brighton West Research Ethics Committee.

Do I have to take part?

No - if you don't want to take part any care you receive will continue as normal

What will happen if I don't want to carry on with the study?

You can stop filling out the questionnaire and you can choose to not hand it in. But after you've left, we may not be able to destroy it as we won't know which is yours.

What are the possible benefits of taking part?

We cannot say the study will help you directly but we hope that sexual health service providers will act on the recommendations from the study.

What are the possible risks of taking part?

The questionnaire includes sensitive questions about sexual behaviour, infections and about pregnancy, which you may find upsetting. A care co-ordinator or researcher will be available to sit with you afterwards if you are upset and we can refer you to counselling services if needed.

What if there is a problem?

Any complaint will be addressed. You can ask to speak to the researchers on 07934 627348 or complain formally through the NHS Complaints Procedure on 01903 843026. The study is indemnified by Sussex NHS Research Consortium.

For more information about the Women's Health study please contact Leanne on 07934 627348

SUPPORT FOR PARTICIPANTS

COMPLETING THE QUESTIONNAIRE:

Researcher

Key worker

Alone

AFTER COMPLETION:

Researcher

Key worker

Referral

THE 'WOMEN'S HEALTH STUDY'



IMPACT OF LAY INVOLVEMENT

WHAT DID AND DIDN'T WORK

What didn't work

Recruiting non-service users via advertisement

Some question items too complicated

Hypothetical and preferential items difficult to answer

What did work

Cut irrelevant items

Good uptake from women using services

Maintained safety of participants

Anecdotal reports of therapeutic benefit

ETHICS OF LAY INVOLVEMENT

- Managing boundaries and disclosure
- Making 'real' contribution possible
- Power at the research table

QUOTES

It felt difficult disagreeing with some lay suggestions but then straight away asking them to think of more ideas

We were limited by what the funding was awarded for and that meant that lay opinions were sometimes discarded which felt difficult

The lay researchers anticipated that some women might find particular subjects upsetting, which really helped me to be sensitive when assisting a participant to complete a questionnaire

It was useful to get feedback...about how to draft our questions....making them less embarrassing & more acceptable....and easy to understand without too much medical jargon

IMPACT ON LAY RESEARCHERS

The main 'reward' of being involved in the research project has been to my self-esteem and self-worth. I have felt valued and a necessary part of the group

I have brought to the study life experiences that cannot be found in textbooks or agency statistics

Being part of the team my listening skills have improved, patience and acceptance of other people's rights to talk and have their opinions

At times I have found the medical/research vocabulary to be quite cold & clinical

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