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An alcohol-related liver disease multi-stakeholder hub (ARMS-Hub) to enhance research activity in underserved communities in the UK

Dhanda, A

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An alcohol-related liver disease multi-stakeholder hub (ARMS-Hub) to enhance research activity in underserved communities in the UK

Below is a collection of written notes made by the ARMS-Hub team during virtual and in-person meetings. All meeting transcripts have been deleted as per the study data management plan.

All queries should be directed to the Chief Investigator, Dr Ashwin Dhanda
ashwin.dhanda@plymouth.ac.uk

Stakeholder meeting notes

13 Sep 2023 – Stakeholder meeting 1

Breakout room: engagement/inclusion of people with ArLD:

Groups that are not included in research:

- Group 1 felt that all people with ArLD are marginalised from participation in research and are given less chances to be involved in research than people with other conditions/without ArLD.
- Young people with ArLD
- People experiencing homelessness
- People from the Sikh Community
- People for whom English is not their first language
- People whose drinking is currently considered low risk
- People who are not linked with a research active site
- People who are inpatients and not admitted for transplant

Barriers to participation:

- People have less opportunity to become research participants if they are linked with sites that are not research active
- Consensus that people with ArLD are generally not asked to take part in research
- Cultural reasons – people from communities where drinking is not accepted will be less likely to take part in research
- Geography – travel (expense and time) can be a barrier to participating in research
- Strict exclusion criteria:
 - E.g. being on palliative care – which can change
 - Co-existing MH conditions
- Time of recruitment – people can be asked to participate in research when they are not in a place that they feel they are able to engage.

Breakout room 2: Engagement with research

Main barriers from a researcher perspective are:

- Resources (time, access to research nurses); services and supporting services are already stretched beyond capacity
- Stigma; HCPs have stereotypes of alcoholics
- Lack of knowledge in non-specialist centres; understanding why we are doing research
- Lack of interest
- Lack of pharma investment
- Not part of NHS health agenda 'demand signalling' – how can we prioritise the agenda
- Lack of confidence in research – 'big/scary'/intimidating, may benefit from mentorship

Barriers from a participant perspective

- Not interested e.g. lower than expected recruitment rate for MICAH observational study
- Nihilistic about interventions for AUD
- Not placed in the most deprived areas or areas of need

21 Sep 2023 – Additional in-person stakeholder meeting

Barriers to engaging in ArLD research:

- Ethnic minorities -have a range of barriers to engagement that we will only identify through being proactive in communication with those communities -need proactive support to engage
 - Need to provide all information - PIS; websites etc in primary languages of communities that we want to engage with
 - Basic alcohol /liver disease information needs to be provided in a range of languages – not waiting for people to ask for this (barrier in itself). Need to identify languages communities are comfortable using
 - Understanding of religious/cultural beliefs
 - Working alongside peers directly drawn from and used to engaging with communities
- HCP judgement
 - Assumption that some groups are ‘hard to reach’ -need to have the resource and proactiveness to ask direct questions about engagement with communities. May just not be used to being asked to take part in research/given the opportunity to do so
 - Work to be done to address HCP attitude/beliefs about ArLD and to then encourage patient engagement in ArLD research – not to make the assumption that patients won’t want to take part in research/are unable to take part in research
- LGBTQ+ community
 - Higher prevalence of dual diagnosis
 - Greater stigmatisation and marginalisation
- Patients early in disease journey – usually people with advanced disease access services and are recruited to research in ArLD -less inclusion of patients upstream/ people who are not yet ill
 - Disorder of disengagement
 - More likely to be disconnected with
 - Services
 - Social networks
 - Less likely to engage
- Culture
 - To a point alcohol use is viewed as acceptable/encouraged and then reaches an unacceptable point.
 - Need more behavioural interventions
 - Changes in young people and reduction in alcohol use
 - May be a shift to the use of recreational drugs
 - Those still using alcohol - at higher rate??
- Heavy drinkers who do not realise they have a problem are hard to identify and access
- Not many opportunities for people with ArLD to engage in research.

4 Oct 2023 – Stakeholder meeting 2

Stigma

Alcohol dependency not seen as a Public Health issue

Heavy glamourisation of alcohol, marketing

For patients: shame and guilt, self-inflicted

Family: doesn't understand it's not self-inflicted, stigma perpetuated by society also impacts how they deal with their loved ones

Education is a big factor: less discrimination from doctors and nurses and more from HCAs and the other patients (refusing to be in the same room, telling them their NHS rights should be taken away)

Low health literacy: Until it starts to go wrong, then they don't know where to go for the evidence based help you talk about Hepatology. People don't even know that's anything to do with the liver. If they look it up and Google it wrong, it could be lizards

Language: needs to be less technical and considerate of how difficult it is for the general population → segregates the small group of people who actually understand it

Access to hepatologists is limited and the access to specialist tests is limited as well

Stereotype of what a person with alcohol dependence looks like, "the man in the bench"

Health professionals being condescending, speaking down to patients

Alcohol industry generates a massive amount of money for the government.

Inclusion/ engagement of patients

Access: most patients are actually happy to engage but they are not aware of what research is taking place

Some people might find it triggering

Self-stigma: people ashamed to admit they have a drinking problem, hiding from others

Nihilism

Engagement of HCPs

Few hepatologists – not enough time to devote to research

Less doctors applying for research grants as they are too exhausted from clinical work

Worse post-covid - less workforce, some doctors were sent to medical wards and can't go back to gastro

A lot of hcps would rather not work with ArLD as it's "self-inflicted"

Solo researchers, lack of interaction and sharing experiences "coming together"

9 Nov 2023 – Stakeholder meeting 3

Self-stigma:

- Feelings of shame, lying to doctors with fear of judgement
- Guilt while in hospital for “taking up a bed”
- Fear of:
 - being judged by people providing care
 - losing their job
 - losing their children

Public stigma:

- Culture of alcohol use in UK:
 - **Easy access** to alcohol
 - **Glamorisation** of alcohol consumption
 - Socially acceptance of “habitual drinking” and peer pressure vs stigma when people ask for help
- Lack of understanding (functioning alcoholics, “why don’t you just stop?”, people think that having a high tolerance to alcohol is a good thing)
- People think it is a choice/ lack of will power
- Stereotype of what an alcohol dependent person looks like
- HCPs tend to assume people with ArLD will not be willing to take part in research
- Public perception influences Government priorities

Structural stigma

- Present all the way through healthcare services, not just primary care but also being referred and accessing specialist care timely
- Lack of research on why people drink – treatment for liver is only part of treatment, there needs to be investigation on why people drink

Solutions proposed

- Early education in schools
- Students visiting support groups and associations and interacting and hearing people’s experiences
- The Shock factor: pictures, statistics, knowing someone who was very ill with ArLD
- Peer training (perhaps mirroring the hep C project) can help build up trust and confidence
- Easier access to information: e.g. leaflets at GP surgeries

- Education of the public: TV ads and magazines/ newspapers, documentaries about liver disease, images and information about damages of alcohol consumption in alcohol bottles
- Biomedical scientists communicating the findings of their work more effectively with the public
- Use social media to educate and raise awareness: numbers, images (of sick liver) and stats (graphs etc)
- The more you talk about it the more stigma drops
- Share more positive stories on the benefits of stopping drinking rather than the negative side to stop people from losing hope.

22 Nov 2023 – Stakeholder meeting 4

1. Accessibility

Difficult to engage as researchers want studies to be successful which causes lack of representation

Lack of awareness of public around alcohol dependency (physical dependency)

Carers are told they can't do anything for their loved ones but when patients are dependent on alcohol they often are not able to function (self refer) – lack of recognition from healthcare services and law that people have no capacity but their carers have no legal right to advocate for them

Other systems way of working is a barrier to alcohol services – MH for example

Alcohol services need re-designing in terms of primary and secondary care – people go to GP then sent to hospital and there isn't much help they get so they don't go back and get "lost" – separate alcohol from other substance use services – services are designed because of funds but not patient centred (for example nurses who work in alcohol services also work with other substances)

Study being conducted has workers going to reach out patients – but they only reach people once they are known to services, we want to get them before they get sick

We need more funding on stigma research

2. Education and awareness

People don't understand units, including HCPs

Harmful drinking is variable depending on the person, comorbidities etc

Education: schools, universities, local authorities, can't be down just to HCPs, in primary care should be all HCPs not just GPs, also information in sitting rooms, social marketing and media campaigns

Education around pressures: a lot of it comes from family members

Strategies: social media, people with lived experience (the impact of a human story)

Hear about people's experiences and with a bit of hope at the end, leaflets with info on the harms of alcohol

No commercial nationwide campaign around alcohol use – Government won't support because of revenue

Educate HCPs: there's still institutional stigma (paramedics, triage nurses)

14 Dec 2023 – Stakeholder 5 meeting notes

Question 1: Disconnect between liver and mental health services

There is both a lack of availability and lack of knowledge around talking therapies. Too much reliance on pushing pills instead. Also some services do not accept people actively drinking as they are unable to engage with psychological therapy.

No joined up care plan or sharing of care

Lack of recognition of liver issues in MH services

MH is seen as secondary to physical health issues. No one asks when on the liver ward. No holistic care.

Question: How can MH services best be integrated into liver services?

Alt: What methods could be used to improve MH integration with liver services?

- What is already known / tested?
- Can liver HCPs be upskilled in MH diagnosis and management?
- What is the best service design for an integrated liver/MH service?

Question 2: HCP perceptions

Education is key

Some examples already exist e.g. 'Stories from a bottle' is an e-learning for health as a tool to tackle stigma.

Thoughts that e-learning is not effective. Would prefer an in-person event

Must involve PWLE.

All HCPs including front line staff (receptionists/ admin team) should be targeted

We didn't discuss medical students but this would also make sense.

Question: Can an educational package co-designed by PWLE and stakeholders be used to reduce stigma in HCPs?

- What has already been done?
- What kind of package can be developed and how can it be deployed?
- What anti-stigma intervention should it contain?

Question 3: lack of knowledge of alcohol harms

There needs to be education around the broader harms of alcohol including cancer and impact on people around them

Also consider harms of lower level alcohol use

What are units

Could also pair with a public health approach – messaging, billboards, posters etc

Education – should be at every level. Particular focus on school age children.

There are already existing programmes e.g. NACOA go into schools with PWLE

Education needs to be given by PWLE.

Should also use social media

Question: Can we design and implement a diverse educational package to educate both young people and adults about the wider harms of alcohol?

- What does the package contain?
- How will it be delivered?
- What info does it need to contain?

Patient, Public Involvement and Engagement (PPIE) meeting notes

8/9/23 – PPIE meeting 1 (virtual and in-person)

Stigma

- Self-stigma: lying to doctors with fear of judgement; guilt while in hospital for “taking up a bed”
- Public stigma: lack of understanding from the public, people think it is a choice and lack of will power
- Lack of knowledge: people think if you are functioning you are not an alcoholic
- Easy access to alcohol – vs access to cigarettes or medications like paracetamol, “It’s legal, it can't be that bad”, petrol stations
- Glamorisation of alcohol consumption: ads, TV shows, social media - “mummy wine” culture, “wine o'clock”

Healthcare access

- Inconsistencies in treatment across Trusts
- Not enough knowledge – gastro doctors are not well equipped
- Lack of funding:

Patients denied counselling until 3 months sober

1 year queue in NHS for counselling

Less social workers in hospitals, no continuity of care after discharge

Support groups struggle with funding, some close leaving people at risk of

27/9/23 – PPIE meeting 2 (virtual and in-person)

Stigma

- Causes of self stigma – when does it come?
- Stigma based around people in certain jobs.
- AUD not covered in equality act – can be discriminated against by employer
- Language – alcoholic
- Fear that social services would get involved.
- Perceptions – lack of education/awareness e.g. having high tolerance to alcohol is not a good thing
- Healthcare issues causing stigma
- Not in isolation – alcohol use is a coping mechanism; after episode of trauma; lack of interest why people might have a problem
- Alcohol is not for fun – reaction to the situation
- Services not joined up or open enough
- GP good but alcohol service rubbish – not connected
- Knocked back by GP – didn't care; Hospital consultant dismissive
- Patients to provide training session on ward – reduce stigma from nursing staff
- Lack of knowledge across sector including hospital setting
- Stigma thrown at you by working in the sector
- Improve knowledge of prevention; understanding of outcomes
- Equity in sharing voices – pay for their time
- Familial influences – ARLD runs in families; encourage drinking
- Disparities in outcomes despite similar levels of alcohol use
- Peer/family pressure to drink
- Role modelling of socialising without alcohol – example from school that excluded alcohol; schools are highest number of licenced premises in UK
- Stigma experienced from HCP; judged on appearance; mistreated by HCPs; lack of care in hospitals (generally)
- Assumptions made by public – don't realise that you don't like drinking; no understanding about addiction; people have preconceived ideas about how you looked after yourself
- Each visit to hospital, self-stigma increases
- Relationships – you close down and isolate yourself; Things got worse during lockdown with more isolation
- Public perception has been slightly improving; more openness but people are still too wrapped up in their own lives to care.

Engagement

- Services are not very good. Challenges with understanding what is being said. What do they do? What treatment is there?
- Education not there on how to support ARLD.
- GP was a barrier – can't get appointment;
- Research – unknown what is out there

- Patient voice? Will that help
- Inconsistency around country
- How to translate across country
- Where to look for information? How to access it? Other forms apart from digital
- How to engage people in research in early phase of disease? Terminology; lots to take in; challenges at that time.
- Perception that people with ARLD don't have ability to understand condition

Language

- Mixed feelings about the term 'alcoholic'. Could use the term addict rather than alcoholic. At AA meetings you have to say you are an alcoholic – makes you feel that you will never recover.
- Depends how the word is used – can be in a non-stigmatising way
- Recovering alcoholic might be more acceptable

1/11/23 – PPIE meeting 3 (virtual and in-person)

Self/public stigma

- Education/awareness
 - Consider educations in secondary schools. Primary is too young and they are still kids.
 - Increase profile through media e.g. one participant mentioned that they learned a lot about alcoholics through watching Eastenders; could use celebrity alcohol recovery stories
 - Main theme was to have input from people with lived experience (PWLE) e.g. recovering alcoholic
 - Much better than government policy – as they lack credibility
 - Could be more holistic – focus on healthy living rather than just alcohol – exercise, eating well etc; make it more normal to look after your liver
 - Could also tackle people when they have been admitted to hospital – they will have been detoxed and might be more receptive. Could use PWLE for this.
 - Peers are honest, better rapport.
 - Engage with deprived communities eg rough sleepers, hostels
 - Use leaflets / online material which puts a positive spin on things
- Language
 - Minimise scariness of the language – could refer to liver damage rather than alcohol-related liver disease.

HCP stigma

- Needs education – build into training but also refreshers for qualified staff as people become complacent.
- Example of medical students attending sessions at Hamoaze was considered a very positive methods – meeting real people, learn how to talk to them, reduce barriers in the future.
- HCPs need better understanding of the condition and to learn how to talk about it to patients.

Engagement

- Accessibility to services
 - Nothing for people who work – need to be unemployed to access most services during daytime
 - Drop in centres
 - Better mental health services
 - Reduce stigma of attending – ensure that there is a clear message that it is OK to attend even if still using alcohol; whatever stage of recovery
 - Improve accessibility to AUD medications
- Incentives
 - Paid for time
 - Healthy living voucher
 - Cover costs of transport to appointment (not just reimbursement)
- Research engagement
 - People switch off when talking about science

- Needs to be short, using multimedia
- Simple basic language
- Follow-up engagement
 - Community based
 - Peer support (Similar model to HepC peers would be helpful)
 - Domiciliary visits – use phone/video call etc