Supporting Under-Represented Groups

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An under-represented or minority group can be defined as

'A group numerically inferior to the rest of the population of a State, in a non-dominant position, whose members - being nationals of the State - possess ethnic, religious or linguistic characteristics differing from those of the rest of the population and show, if only implicitly, a sense of solidarity, directed towards preserving their culture, traditions, religion or language'
(United Nations Human Rights 2010, p. 2).

Several barriers to hospital based rehabilitation have been identified. These may lead to limited access to services for certain under-represented or 'minority groups' such as women, ethnic groups, individuals with low socioeconomic status, living in rural areas, the elderly and those with physical and/or learning disabilities (Doherty et al. 2016).

When facilitating the Heart Manual, it is important to be aware of any barriers or issues which may directly affect the individual's ability to participate in a cardiac rehabilitation programme. However, in many cases, the flexibility of the manual can help people overcome some of these barriers. Here the facilitator plays a crucial role in the assessment process, harnessing their communication skills and expertise to explore the individual's requirements and support them to find solutions to any obstacles which may delay or limit their recovery.

Age

Age can present barriers to participation in cardiac rehabilitation for a number of reasons. Some older people may express apprehension regarding their ability to make lifestyle changes, while others may voice concern regarding the exercise component of a rehabilitation programme or feel that additional medical conditions may restrict their ability to participate. Vice versa; those of a younger generation who may feel that the programme is unacceptable due to the predominantly older population who participate in traditional rehabilitation programmes.

In this respect, the Heart Manual does not promote a one-size-fits-all ethos, but aims to meet the needs of each individual through the appropriate selection of information and exercise guidance. It is important to remember that the exercises provided are offered as a suggestion 'to get started'. In this respect, it is the role of the facilitator to negotiate appropriate levels of physical activity with the individual while considering other resources which may be more suitable to address any unmet need. This may include referral to services where exercise is tailored to the individual's capacity, seated exercise classes or exercise specialist input.

Gender

In general, women are less likely to complete traditional cardiac rehabilitation than men. This may be because: women are more likely to display different signs and symptoms of CAD; women may view CAD as a predominantly male condition; or that believe that their symptoms are due to a different cause, resulting in misconceptions and a lack of attendance or adherence (Doherty et al. 2016). Women are also increasingly likely to be in paid and unpaid employment (International Labour Organisation 2016), limiting the time available to focus on self management and recovery.

The Heart Manual embraces a cognitive behavioural approach, aiming to clarify misconceptions which may limit engagement with the rehabilitation process at an early stage. The approach also aims to help individuals consider how best to manage their recovery, whilst acknowledging time pressures and responsibilities.

Several factors make the participation of women in cardiac rehabilitation important. Compared to men women find it more difficult to quit smoking and are more susceptible to relapse. Research has shown that women have different reasons for smoking cigarettes to men and may use smoking as a way to deal with stress and anxiety or to control their weight (Memon et al 2106). The amount of alcohol consumed by women has increased and the gap between men and women's alcohol use is closing (Slade et al 2016). It is also known that women are less physically active on a regular basis than their male counterparts.

Delivering support at the right time and in the right place may be one of the key issues when addressing the uptake of rehabilitation in women. As the Heart Manual

is predominantly supported in the home environment, it naturally reduces the time demands placed on the individual compared to attending even a community based programme.

Disabilities

Depending on the disability experienced, there may be various physical and cognitive barriers which can limit the individual's ability to fully access and participate in cardiac rehabilitation. Some of those with congenital disabilities may be at greater risk of heart conditions than the general population.

Difficulties may range from sensory impairments such as visual or auditory disturbance, which may simply be addressed by offering information in a variety of formats such as talking books, brail, large font and subtitled DVD's; to those with more profound disabilities resulting in severe physical and mental dependency.

Some research suggests that those with learning disabilities maybe less likely to participate in physical activities, with only 8-16% being physically active compared to 30-47% of the general population, while other studies have shown that barriers to physical activity in this group are similar to those of the general population (Melville et al 2007). In this respect, rehabilitation services must try harder to assess individuals with learning disabilities in order to address health inequalities.

The Heart Manual has tried to tackle some of these issues by offering an individually tailored exercise and educational programme, while encouraging facilitators to seek out specialist assessment and support when necessary. To make the Heart Manual as accessible as possible, all manuals are printed in Arial size 14 font and have a low reading age. Also the font size can be increased in the digital versions of the manuals.

For those who live with more severe disabilities, the priority must be to ensure quality of life whilst offering support and information to assist the individual and carer to minimise dependency. In this situation it is often the family or carer who requires the greatest level of support and education in order to clarify any misconceptions they may have regarding their loved one's prognosis. To ensure equity, rehabilitation programmes must now strive to offer a more holistic approach to care delivery, by

encompassing the wider educational needs of the carer and the family (Astin et al. 2008) even when the individual experiencing CAD cannot participate in formal rehabilitation programmes.

It is estimated that 1:6 of the adult population have some degree of difficulty with the written word. This situation is compounded by the use of medical terms and jargon increasing the propensity towards 'health' related illiteracy. This is particularly important as low health literacy poses a major barrier to educating people with a long term condition such as cardiovascular disease (Sørensen et al 2015).

Socio-economic status

Belonging to a lower socio-economic group has been found to be an independent risk factor for CAD (Scottish Intercollegiate Guidelines Network 2007). This is of particular concern when we consider the other health and behavioural issues which may affect these individuals.

Those who live in poverty are known to be at greater risk of experiencing mental health issues (Stewart-Brown 2015), which may make them more susceptible to the psychological problems which are commonly experienced following a diagnosis of CAD, such as anxiety, low mood and depression. It is also common for people from a low socio-economic status to experience lower levels of self-efficacy, limiting their perceived ability to take control of their circumstances and make health related choices (Richardson 2001).

Food insecurity is described as "the inability to afford or to have access to, food to make up a healthy diet." Individuals who are unemployed or on low incomes are more likely to experience food poverty than those in employment or on higher incomes. In comparison to the general the population, those in low income households eat less: fruit and vegetables; high fibre cereals; skimmed or semi-skimmed milk; or oily fish/canned tuna. Similarly, this group eat more processed foods, whole milk, fat spreads and sugar (Konttinen 2012). Their diet may also be hampered by limited access to cooking equipment and lack of the knowledge and skills required to prepare healthy food (Henderson et al. 2007).

Other behaviour related issues include levels of smoking and alcohol consumption. Studies have shown that those from a lower socio-economic background have a higher rate of tobacco use than those from higher socio-economic groups. This is associated with a tendency towards smoking more cigarettes, deeper inhalation and smoking more of the cigarettes they use (Office for National Statistics 2015). Alcohol related morbidity is greatest among living in the most deprived areas (Brown et al. 2016).

Rural areas

Those living in rural areas face considerable barriers in accessing cardiac rehabilitation. These may involve distance from the rehabilitation classes, cost and transport problems. The issue may be compounded by low social economic status (SES). Those living in rural areas with SES are less likely to be referred, enrolled and to participate in CR programmes (Shanmugasegaram et al 2013, Menezes et al 2014). Heart Manual as a home based programme is a cost effective intervention for those not able to attend their local centre or hospital (Blair et al 2011).

Ethnicity

Ethnicity can be described as being “rooted in the idea of societal groups, marked especially by shared nationality, tribal affiliation, religious faith, shared language, or cultural and traditional origins and backgrounds” (Bhopal 2004). Because defining every ethnic group within the country is an extensive task, the Heart Manual has therefore chosen to focus on those groups who are at significantly higher risk of CAD or have limited access to cardiac rehabilitation.

South Asian ethnic groups

The South Asian population accounts for a fifth of all worldwide deaths from coronary heart disease (CHD). Reasons underlying the increased CHD mortality among South Asians remain unclear (Tan et al 2014). This section explores several areas relevant to the South Asian population that require a greater awareness when delivering the Heart Manual. These issues may apply to others, but it is important to

note that other ethnic groups may also have separate issues specific to culture, religion or lifestyles.

Some people from South Asian descent may also be more inclined to relate their illness to their religious beliefs or fate and perceive that they have little control over their illness (Grewal et al 2010, Tirodka et al 2011). This is particularly important for the facilitator to be aware of especially when discussing behaviour or lifestyle modifications as these beliefs may be a barrier to change.

One significant barrier to participation in rehabilitation programmes is the lack of resources for those who do not speak or read English. This can create problems at several stages of the patient's journey from diagnosis to treatment, and from treatment to rehabilitation. Provision for non-English speakers varies from area to area with some services providing specially-trained link workers to bridge the language gap and aid the rehabilitation process while others offer very limited translation services. It is therefore essential that the facilitator explore and utilise the resources available within their area. In some cases, family members may be willing to provide some translation. However, it is important to be aware that this can place the patient and their family members in a difficult situation, especially when disclosing personal or distressing information (Astin et al. 2008).

Different ethnic groups may consume different types of food, which may be classed as unhealthy. For example, the traditional diet of South Asians in the UK tends to be high in saturated fat (e.g. ghee). However it is important to be aware that not all traditional diets are unhealthy. For example, the diet of Hindus originally from Gujarati is mainly vegetarian. The Heart Manual has several suggestions on alternatives to unhealthy foods. The facilitator can also support by suggesting alternative cooking methods and tips. Facilitators may also need to take into account religious practices and festivals which may have an impact on an individual's dietary intake (e.g. Ramadan).

Sedentary behaviour is common in the South Asian population with few than 11% undertaking regular physical activity at the recommended levels in the UK (Horne 2013). Other qualitative studies (Sriskantharajah and Kai 2007; Horne et al 2013) have reported that many physical exercise classes are inappropriate for women as they are often mixed gender groups. For example, certain types of exercise can be

excluded due to concerns regarding modesty, especially if in a mixed sex environment. Although this may be a concern for many women, South Asian women may face additional barriers to physical activity due to their religion. As the Heart Manual encourages patients to find acceptable ways to incorporate activity into their lifestyles, these barriers can often be overcome. The facilitator and the patient can work together to explore the most appropriate method of exercise for the individual.

The prevalence of smoking within different South Asian groups varies (Lip et al. 2007). For example, although certain religions view tobacco use as a taboo, some groups smoke cigarettes; others smoke Asian cigarettes (biddi) and some chew tobacco in the form of paan (Action on Smoking & Health Scotland 2011). Tobacco (or shisha) is also smoked using a hookah pipe by some South Asians and Arabs. Although the Heart Manual provides tips on giving up tobacco use, it is important to recognise behaviours which are often identified as social norms. In these circumstances it would be appropriate to ensure information and support is offered sensitively while utilising local resources to address these needs.

Gypsy and travelling groups

Van Cleemput et al (2007) noted that over the last 500 years there have been 300,000 Gypsies and Travellers living and working within the UK. These groups may live a nomadic existence while others may live within authorised sites (Van Cleemput 2008).

Missed and/or interrupted education has resulted in many Gypsy and travelling individuals being unable to access information. Unfortunately this has led to the automatic assumption that this is secondary to special educational needs when in fact it is more likely to be as a result of limited opportunities to learn or progress (Parry et al. 2007). The Office for Standards in Education, Children's Services and Skills has shown that those of an Irish heritage have the lowest educational results of any minority ethnic group and are the group most at risk due to educational limitations (Department for Education and Skills 2003).

In relation to health status, Parry et al (2007) carried out a study which indicated that Gypsy/Travellers have significantly poorer health status compared with other UK residents

A higher prevalence of self reported ill health was also noted in particular: symptoms of anxiety, chest pain, respiratory problems and arthritis, with those who rarely travel having the highest rate of ill health (Van Cleemput et al. 2007.

Parry et al (2007) describe three major themes in relation to health beliefs within the Gypsy and travelling populations, these being: stoicism and tolerance of ill health; a fatalistic view of illness being an inevitable consequence of social circumstances; and a lack of confidence in medical treatment and health practitioners, with greater value being placed on the support and advice offered by family carers. This has resulted in poor attendance at screening clinics and use of preventative therapies, some of which may be associated with accessing systems which are frequently culturally unsympathetic (Parry et al. 2007).

A systematic review of health and service utilisation of the Roma population (Cook et al 2013) comprising English Romani Gypsies, Irish Travelers, and Roma from Central and Eastern Europe supports the earlier findings of Parry et al. (2007) above.

A lack of continuity in care as well as the restrictions imposed on the individual due to literacy barriers can have a huge impact on their capacity to access rehabilitation as well as health related information. When working with these individuals it would be prudent to seek out specialist practitioners who have a greater appreciation of the circumstances of the local travelling population as well as an ability to assist with dissemination of health-related information.

People in prison

Over the last five years we have seen an increase in delivery of Heart Manual training to health professionals working with people in prison who have had an MI or revascularisation, and the supply of Heart Manuals to this population. Our experience shows us that the Heart Manual programme is well suited to those in prison. Use of the Heart Manual programme is a solution to the obvious barrier to cardiac rehabilitation facing this population as they are unable to attend community or hospital based classes.

The proportion of older prisoners in the total prison population is increasing (NICE 2016). Older individuals (50+) fastest growing population in prisons – increased from

~7% in 2005 to 15% in 2016. This trend seen in both males and females. (Allen and Dempsey 2016). As a consequence there is a rising demand to maintain health and manage chronic conditions such as heart disease (O'Hara et al 2016). There is also a strong association between unmet physical health needs and depressive symptoms (O Hara et al 2016). This is another concern as depression is a well known risk factor for secondary infarction. Cardiac risk factors such as smoking, obesity and low physical activity are also common in the prison population (Donahue 2014). At time of writing there is also a NICE guideline on the mental health of adults in contact with the criminal justice system which would be worth consulting when it is published (due February 2017).

References

Allen, G. and Noel Dempsey, N. 2016. *Prison Population Statistics.* London: House of Commons Library.

Astin, F., Atkin, K. and Darr, A. 2008. Family support and cardiac rehabilitation: a comparative study of the experiences of South Asian and White-European patients and their carer's living in the Kingdom. *European Journal of Cardiovascular Nursing,* 7(1), pp. 43-51.

Bhopal, R. 2004. Glossary of terms relating to ethnicity and race: for reflection and debate. *Journal of Epidemiology of Community Health* [online]. December, vol.58, pp.441-445 [viewed 6th December 2016]. Available from: doi:10.1136/jech.2003.013466

Blair, J., Corrigall, H., Angus, N.J., Thompson, D.R. and Leslie, S., 2011. Home versus hospital-based cardiac rehabilitation: a systematic review. *Rural and Remote Health*, *11*(2), pp.1-17.

Cook, B., Wayne, G.F., Valentine, A., Lessios, A. and Yeh, E. 2013. Revisiting the evidence on health and health care disparities among the Roma: a systematic review 2003-2012. *International Journal of Public Health* [online]. October, vol.58, pp.885-911 [viewed 6th December 2016]. Available from: doi:10.1007/s00038-013-0518-6

Department for Education and Skills. 2003. *Aiming High: Raising the achievement of Gypsy Traveller pupils - a guide to good practice.* DfES/0443/2003. Nottingham: DfES Publications.

Department of Health. 2000. *National service framework for coronary heart disease.* Ref 16602. London: Department of Health.

Doherty, P., Petre, C., Onion, N., Harrison, A., Sumner, J., Cardy, K. and Tang, L. 2016. *The National Audit of Cardiac Rehabilitation: Annual Statistical Report 2016* [online]. The University of York: The British Heart Foundation National Audit. [viewed 6th December 2016]. Available from: www.cardiacrehabilitation.org.uk

Donahue, J. 2014. Coronary Artery Disease in Offender Populations: Incarceration as a Risk Factor and a Point of Intervention. 2014. *Journal of Correctional Health Care* [online]. July, vol.20, no.4, pp. 302-312 [Accessed 5th January 2017]. Available from: doi:10.1177/1078345814541534

European Monitoring Centre on Racism and Xenophobia. 2003. *Breaking the barriers - Romani women and access to public health care.* Luxembourg: Office for Official Publications of the European Communities.

Fischbacher, C.M., Hunt, S. and Alexander, L. 2004. How physically active are South Asian in the United Kingdom? A literature review. *Journal of Public Health,* 26(3), pp. 250-258.

Grewal, K., Stewart, D.E. and Grace, S.L., 2010. Differences in social support and illness perceptions among South Asian and Caucasian patients with coronary artery disease. *Heart & Lung,* 39(3), pp. 180-187.

Henderson, L., Gregory, J., Irving, K. and Swan, G., 2007. *The national diet & nutrition survey: adults aged 19 to 64 years (Vol. 2). Energy, protein, carbohydrate, fat and alcohol intake.* Norwich: TSO.

Horne, M., Skelton, D.A., Speed, S. and Todd, C. 2013. Perceived barriers to initiating and maintaining physical activity among South Asian and White British adults in their 60s living in the United Kingdom: a qualitative study. *Ethnicity & Health* [online]. April, vol.18, no.6, pp.626-645. [viewed 6th December 2016]. Available from: doi:10.1090/13557858.2013.814762

Information Services Division. 2009. *Alcohol Statistics Scotland 2009.* Edinburgh: ISD.

International Labour Office. 2016. *Women at Work: Trends 2016* [online]. Geneva: International Labour Organization.

Konttinen, H., Sarlio-Lahteenkorva, S., Silventoinen, K., Mannisto, S. and Haukkala, A. 2012. Socio-economic disparities in the consumption of vegetables, fruit and energy-dense food: the role of motive priorities. *Public Health Nutrition* [online]. August, vol. 16, no.5, pp.873-883 [viewed 6th December 2016]. Available from: doi:10.1017/S1368980012003540

Lip, G.Y., Barnett, A.H., Bradbury, A., Cappuccio, F.P., Gill, P.S., Hughes, E., Imray, C., Jolly, K. and Patel, K. 2007. Ethnicity and cardiovascular disease prevention in the United Kingdom: a practical approach to management. *Journal of Human Hypertension,* 21(3), pp. 183-211.

Melville, C.A., Hamilton, S., Hankey, C.R., Miller, S. and Boyle, S. 2007. The prevalence and determinants of obesity in adults with intellectual disabilities. *Obesity Reviews,* 8(3), pp. 223-230.

Memon, A., Barber, J,. Rumsby, E., Parker, S., Mohebati, L., de Visser, R.O., Venables, S., Fairhurst, A. Lawson, K. and Sundin, J. 2016. What factors are important in smoking cessation and relapse in women from deprived communities? A qualitative study in Southeast England. *Public Health* [online]. February, vol.134, pp.39-45 [viewed 22nd December]. Available from: doi:10.1016/j.puhe.2016.01.014

Menezes, A.R., Lavie, C.J., Milani, R.V., Forman, D.E., King, M. and Williams, M.A., 2014. Cardiac rehabilitation in the United States. *Progress in cardiovascular diseases*, *56*(5), pp.522-529.

Nelson, M., Erens, B., Bates, B., Church, S. and Boshier, T. 2007. *Low income diet and nutrition survey: Volume 3. Nutritional status, physical activity, economic, social and other factors.* Norwich: TSO.

National Institute for Health and Care Excellence. 2016. Physical health of people in prison [NG 57]. London: National Institute for Clinical Excellence

Office for National Statistics. 2015. *Integrated Household Survey (Experimental statistics): January to December 2014. Sexual identity, smoking prevalence and perceived general health using data from the Integrated Household Survey* [online]. United Kingdom [viewed 6th December 2016]. Available from: www.ohs.gov.uk

O'Hara, K., Forsyth, K., Webb, R., Senior, J., Hayes, A.J., Challis, D., Fazel, S. and Shaw, J. 2016. Links between depressive symptoms and unmet health and social care needs among older prisoners. *Age and Ageing* [online] January, vol.45, pp. 158-163 [Accessed 5th January 2017]. Available from: doi: 10.1093/ageing/afv171

Parry, G., Van Cleemput, P., Peters, J., Walters, S., Thomas, K. and Cooper, C. 2007. Health status of Gypsies and Travellers in England. *Journal of Epidemiology and Community Health,* 61, pp. 198-204.

Richardson, K. 2001. *Smoking, Low Income and Health Inequalities: Thematic discussion document.* London: ASH & Health Development Agency.

Scottish Intercollegiate Guidelines Network. 2007. *Risk estimation and the prevention of cardiovascular disease.* SIGN Publication No. 97. Edinburgh: SIGN.

Shanmugasegaram, S., Oh, P., Reid, R.D., McCumber, T. and Grace, S.L., 2013. Cardiac rehabilitation barriers by rurality and socioeconomic status: a cross-sectional study. *International journal for equity in health*, *12*(1), p.72.

Slade T, Chapman C, Swift W, Keyes, K., Tonks, Z. and Teesson, M. 2016. Birth cohort trends in the global epidemiology of alcohol use and alcohol-related harms in men and women: systematic review and metaregression. *BMJ Open* [online]. August, vol. 6, pp. 1-12 [viewed 22nd December 2016]. Available from: doi: 10.1136/bmjopen-2016-011827

Sørensen, K., Pelikan, J.M., Röthlin, F., Ganahl, K., Slonska, Z., Doyle, G., Fullam, J., Kondilis, B., Agrafioti, D., Uiters, E., Falcon, M., Mensing, M., Tchamov, K., van den Broucke, S. and Brand, H. 2015. Health literacy in Europe: comparative results of the European health literacy survey (HLS-EU). *European Journal of Public Health* [online]. April, vol.25, no.6, pp.1053-8 [viewed 6th December 2016]. Available from: doi: 10.1093/eurpub.ckv043

Spring, E. 2013. *Disabled People's Lifestyle Survey September 2013.* English Federation of Disability Sport. [viewed 6th December 2016]. Available from: www.efds.co.uk

Sriskantharajah, J. and Kai, J. 2007. Promoting physical activity among South Asian women with coronary heart disease and diabetes: what might help? *Family Practice,* 24(1), pp. 71-76.

Stewart-Brown, S., Samaraweera, P.C., Taggart, F., Kandala, N.B. and Stranges, S. 2015. Socioeconomic gradients and mental health: implications for public health. *The British Journal of Psychiatry* [online]. Vol. 206, pp. 461-465 [viewed 6th December 2016]. Available from: doi: 10.1193/bjp.bp.114.147280.

The NHS Information Centre, Lifestyles Statistics. 2009. *Statistics on Alcohol: England, 2009.* London: The NHS Information Centre for health and social care.

Tan, S., Scott, W., Panoulas, V., Sehmi, J., Zhang, W., Scott, J., Elliott, P., Chambers, J. and Kooner, J.S. 2014. Coronary heart disease in Indian Asians. *Global Cardiology Science & Practice* [online]. February, vol.4, pp.13-23 [viewed 6th December 2016]. Available from: doi:10.5339/gcsp.2014.4

Tan, S., Scott, W., Panoulas, V., Sehmi, J., Zhang, W., Scott, J., Elliott, P., Chambers, J. and Kooner, J.S. 2014. Coronary heart disease in Indian Asians. *Global Cardiology Science & Practice* [online]. February, vol.4, pp.13-23 [viewed 6th December 2016]. Available from: doi:10.5339/gcsp.2014.4

United Nations Human Rights. 2010. *Minority rights: international standards and guidance for implementation.* New York and Geneva: United Nations.

Van Cleemput, P. 2008. Health impact of Gypsy Sites Policy in the UK. *Social Policy and Society,* 7(1), pp. 103-117.

Van Cleemput, P., Parry, G., Thomas, K., Peters, J. and Cooper, C. 2007. Health-related beliefs and experiences of Gypsies and Travellers: a qualitative study. *Journal of Epidemiology and Community Health,* 61, pp. 205-210.

Williams, M.V., Baker, D.W., Parker, R.M. and Nurss, J.R. 1998. Relationship of Functional Health Literacy to Patients' Knowledge of Their Chronic Disease: A Study of Patients with Hypertension and Diabetes. *Archives of Internal Medicine,* 158(2), pp. 166-172.