The Complete Practitioner's Guide

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Foreword

Over the past 30 years, we've begun to understand a lot more about the health inequalities experienced by people with learning disabilities. Health inequalities aren't just differences in health between people with learning disabilities and other people, they are differences that are "systematic, socially produced (and therefore modifiable) and unfair"[1]. The health inequalities experienced by people with learning disabilities are not inevitable, and we collectively have a duty to do something about them.

This is the latest version of the Health Equalities Framework (the HEF+), which uniquely has taken a health inequalities approach to develop a practical tool that "measures the effectiveness of services in taking steps to reduce the different adverse health outcomes experienced by people with learning disabilities" (page 5). It is firmly based on research evidence about health inequalities and has been thoroughly tested in practice. It offers the opportunity to reflect holistically on a person's circumstances while suggesting with some precision where the person needs to be better supported.

The HEF+ can be used to track how individuals are being supported over time, and aggregated to see how groups of people are being supported.

Thanks to the commitment and thoroughness of the authors, the HEF+ has been thoroughly revised and, through the Creative Commons license, has been made freely available for people to use. So use it!

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[1] Whitehead M & Dahlgren G (2006). Concepts and principles for tackling social inequalities in health: Levelling up Part 1. Copenhagen: World Health Organization Europe.

Introduction

The Health Equalities Framework (HEF) was originally developed and launched by a group of four consultant learning disability nurses in April 2013. It was born out of concerns regarding the continuing evidence that people with learning disabilities experience reduced healthy life expectancy (premature and avoidable mortality, and significantly compromised quality of life when experiencing ill health). As these outcomes can be shown to be avoidable and have been widely deemed to be socially unjust, they must be construed as examples of significant health inequities rather than merely the inevitable consequence of carrying a greater burden of health needs.

In 2012 Strengthening the Commitment[2], the report of the UK modernising learning disability nursing review called upon nurse leaders to develop and apply outcomes focused measurement frameworks to evidence their contribution to improving person centred health outcomes. The HEF represents a key response to this recommendation. Based on a sophisticated Microsoft excel workbook, the HEF was made freely available across the UK and all four UK countries are increasingly embedding it into practice.

The HEF was developed on the basis of a series of systematic reviews of the health inequalities experienced by people with learning disabilities which identified and described the five key determinants of health inequalities in this population. The authors ensured the construct validity of the instrument through rigid adherence to the underpinning evidence base, whilst a Delphi approach was adopted to the development of indicators of the impact of exposure to the determinants. The HEF was initially developed as a nursing tool, however, following extensive piloting and consultation, a range of other health and social care disciplines also recognised its ability to reflect outcomes associated with their unique areas of practice. In England, the National Valuing Family forum were consulted at the outset and have subsequently widely advocated its use.

The HEF is not intended to replace other outcome tools that are used in specific settings or for specific interventions; its purpose is to provide a clear and transparent, overarching, health-focused outcomes framework, with a common language that can aid understanding for everyone involved, particularly between commissioning and service provision and across health and social care settings.

The HEF does not cover all outcomes achieved by nurses and other learning disability practitioners within their many diverse and specialist roles, however it does capture the commonality of the universal role and responsibility of all health and social care practitioners to reduce health inequalities for this significantly marginalised population. The HEF is a measure of the impact and outcomes of service delivery, rather than a clinical outcome measure: it does not focus on a medical model of illness, it does not monitor the course of symptoms in the way that many clinical outcome measures do; rather, it measures the effectiveness of services in taking steps to reduce the different adverse health outcomes experienced by people with learning disabilities.

[2] The Scottish Government (2012) *Strengthening the Commitment*. Edinburgh: TSG

The HEF requires practitioners to profile exposure to determinants of health inequalities. The underpinning evidence base clearly shows that improvements in profiles over time are associated with improved healthy life expectancy. As such, the HEF drives practitioners to deliver services to the people they support in a way that reduces the impact of exposure to the determinants of health inequalities. The repeated message from practitioners is that 'you profile someone today and tomorrow you change the way you support them'.

The HEF also however yields a wealth of data that can be anonymised and aggregated, not just about exposure to the determinants but also set against the context of biographical and morbidity date; this then has the ability to both inform public health strategy and allow variances in service outcome to be queried and understood. For those providing direct care and support, the HEF creates a common terminology and focus, it validates and guides practitioners' decision making and establishes a shared objective to reduce health inequalities. As such, in practice, it is not perceived as a bureaucratic process but rather as an informative tool to aid the planning of care and support. At a strategic level the HEF improves the consistency of service responses to healthcare need and helps to eliminate inequitable post code lotteries.

The authors of the HEF have learned many lessons from pilot work and implementation to date across the UK. They have also reflected on the ever evolving evidence base around the factors that continue to drive health inequalities as well as the ways in which they can manifest. They have responded by reviewing and refining indicators of exposure to the determinants of health inequalities and by making improvements to the user interface. In doing so a new updated HEF+ has been developed. This manual has been written to assist practitioners in making the fullest possible use of the HEF+.

Background

In 2011, the Learning Disability Public Health Observatory[3] reviewed the wide ranging data gathering that takes place around the health circumstances and experiences of people with learning disabilities. They examined total-population health monitoring frameworks, along with those that apply within primary and secondary healthcare settings and found that there was no authoritative comparative national dataset relating specifically to the health of people with learning disabilities as a discrete population. It was suggested that, as new arrangements evolve around the modernisation of healthcare delivery, a wider information set would be required to inform decisions about the services that should be developed and how best to meet the healthcare needs of the learning disabled population, as well as to provide essential assurances that the public sector equality duty towards people with learning disabilities (established by the 2010 Equality Act[4]) is being honoured.

The HEF and now the HEF+, works by monitoring the degree and impact of exposure of people with learning disabilities to acknowledged, evidence based determinants of health inequalities. The resulting profile is not dependent on the complexity of a person's needs, their specific conditions or presentations, but rather on the systems around them that ensure that their needs and long-term conditions are appropriately identified and responded to; and that individuals are receiving the right support. The HEF+ monitors outcomes achieved by services rather than the course of an illness or the severity of symptoms. The validity of such an approach rests in the strength of the underpinning research which clearly identifies serious health inequalities are the inevitable future consequence of unmitigated exposure to the determinants.

Detailed evidence reported by the Public Health Observatory[5] shows there to be five clearly discernible determinants of the health inequalities commonly experienced by people with learning disabilities:

- Social determinants
- Genetic and biological determinants
- Communication difficulties and reduced health literacy
- Personal health behaviour and lifestyle risks
- Deficiencies in access to and quality of health provision

It is clear from the evidence, that for a person with a learning disability, the greater their exposure to these determinants the greater the likelihood of them experiencing otherwise avoidable negative health outcomes. The consequences of these inequalities are significant and include premature mortality, increased experience of ill health and impoverished quality of life.

The review of underpinning evidence and consultations undertaken during scale development, led to discrete sets of Health Inequality Indicators being identified for each of the five determinants. The breadth and range of these indicators helps to define the range and scope of legitimate health interventions i.e. it explains the need for health professionals to address important social factors which are associated with adverse health outcomes, as well as to support mainstream health services to become more accessible to people with disabilities. Importantly it provides a rationale for health practitioners to work within the context of a social

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[3] Glover et al (2011) *NHS Data Gaps for Learning Disabilities* Learning Disabilities Public Health Observatory
[4] *Equality Act 2010* London: HMSO
[5] Emerson et al (2011) *Health inequalities and people with learning disabilities in the UK: 2011.* Learning Disabilities Public Health Observatory.

model of health, where social care activity might otherwise be considered not to be legitimate healthcare activity.

Understanding the causes of health inequalities

There is a well-established body of evidence that shows that health is determined by a wide range of different factors[6]. The causes of poor health in the general population are typically recognised as including poor diet, poor educational attainment and unsafe environment. These are known to be unevenly distributed across society - the risk of poor health decreases as social class increases. Lower social positions arising from, for example, low income, gender assumptions, having a disability, belonging to a minority social group or combinations of these factors, reduce opportunities to access resources needed for health such as good housing and food, social mobility, or attending the best schools. Therefore, strategies to improve health require improvements in, for example, housing, food, and environments; and strategies to tackle health inequalities require not only these but also action on the causal factors for social inequalities: discrimination and lack of access to high quality resources.

The Improving Health and Lives Learning Disabilities Public Health Observatory has published a series of reports which have described the health inequalities experienced by people with learning disabilities[7,8,9] and the factors that appear to drive, or predict, them. They cite established, underpinning evidence relating to each of the five determinants of health inequalities and this proved central to the development of the HEF+. There follows a summary of what has been reported in relation to each of the determinants. Readers should consult to the original reports for a fuller account.

[6] Buck, D and Maguire, D. (2015) *Inequalities in life expectancy* London: The Kings Fund
[7] Emerson and Baines (2010) *Health Inequalities and people with learning disabilities in the UK: 2010.* Learning Disabilities Public Health Observatory.
[8] Emerson et al (2011) *Health inequalities and people with learning disabilities in the UK: 2011.* Learning Disabilities Public Health Observatory.
[9] Emerson et al (2012) *Health inequalities and people with learning disabilities in the UK: 2012.* Learning Disabilities Public Health Observatory.

Social determinants

Refers to exposure to social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness.

People with learning disabilities, especially people with less severe learning disabilities and those who do not access specialist learning disability services, are more likely to be exposed to common 'social determinants' of (poorer) health such as poverty, poor housing conditions, unemployment, social disconnectedness and overt discrimination. The link between exposure to these adversities and health status is at least as strong for people with learning disabilities as it is in the general population. Furthermore it has been shown that over time, families with a child with a learning disability are more likely to experience relative poverty and are less likely to be able to escape this situation than other families. It has been suggested that this increased exposure to socio-economic deprivation accounts for:

1. 20–50% of increased health adversity amongst children and adolescents with learning disabilities.
2. 32% of the increased risk of conduct difficulty and 27% of the increased risk of peer relation problems amongst 3 year old children with developmental delay.
3. 29-43% of the increased prevalence of conduct difficulties among children with learning disabilities or borderline intellectual disability as well as 36-43% of the increased difficulties with peer relations.
4. A significant proportion of increased rates of self-reported antisocial behaviour among adolescents with learning disabilities.

The importance of poverty, poor housing, unemployment and social isolation as factors leading to poorer health are well known; material deprivation is associated with poor housing, increased exposure to infection, poor nutritional status etc. People with learning disabilities are more likely to experience some or all of these factors.

Exposure to bullying at school and overt discrimination (including hate crime) in adulthood, both predictive of poorer general health status amongst adults with learning disabilities, are frequently experienced by people with learning disabilities.

People with learning disabilities from black and minority ethnic groups are known to be more likely to be exposed to socioeconomic deprivation and overt racism, and are consequently also more likely to face health inequalities than people with learning disabilities from majority communities.

Genetic and biological determinants

Refers to genetic and biological conditions physical and mental health problems which are specifically associated with learning disabilities.

People with moderate to profound learning disabilities are more likely than the general population to die from congenital abnormalities. Many genetic and biological conditions which give rise to learning disabilities are also associated with an increased risk of further physical and mental health conditions, for example:

- Congenital heart disease is more prevalent among people with Down syndrome, Williams syndrome and Fragile X Syndrome;
- Early onset dementia is more common in people with Down syndrome;
- Hypothalamic disorders are more prevalent among people with Prader-Willi syndrome;
- Mental health problems and challenging behaviours are more prevalent among people with autistic spectrum conditions, Rett syndrome, Cornelia de Lange syndrome, Riley-Day syndrome, Fragile-X syndrome, Prader-Willi syndrome, Velocardiofacial syndrome / 22q11.2 deletion, Williams syndrome, Lesch-Nyhan syndrome, Cri du Chat syndrome and Smith-Magenis syndrome;
- Obesity is more prevalent among people with Prader-Willi syndrome, Cohen syndrome, Down's syndrome and Bardet-Biedl syndrome;
- Sleep problems are more prevalent among children with Williams Syndrome and Down's syndrome.

Research has highlighted the possible interactions between genetic determinants of poorer health and the environment. Genetically determined preferences may create a motivational state that leads to the development of behaviours that are maintained by environmental contingencies, for example, individuals with Angelman syndrome often find social contact extremely pleasing and may therefore come to display aggressive or self-injurious behaviours in order to meet an otherwise unfulfilled need to access unusual amounts of social contact. Similarly, dysfunction of the Hypothalmic Pituitary Axis in people with Fragile-X syndrome is associated with social anxiety, consequently people may have a need to avoid busy social settings and develop behaviours which others consider challenging as a strategy to meet this need.

It is apparent that environmental conditions can increase the expression of genetically determined risks or that genetic factors and environmental factors may independently lead to the same health outcome. For example, Attention Deficit Hyperactive Disorder (ADHD) appears to have a genetic component involving the regulation of dopamine and serotonin neurotransmitters in the brain (which can lead to problems with executive function control or impulsive behaviour); however, the in-utero environment can increase risk of ADHD if the developing foetus is exposed to alcohol or tobacco and the child-rearing environment can increase risk if the child has been exposed to trauma or neglect.

There are significant variations in NHS total expenditure and expenditure per person on specialist services for people with learning disabilities across different areas of England, with lower spending in rural areas and significant variation in the services provided to people with learning disabilities by specialist NHS Trusts.

Communication difficulties and reduced health literacy determinants

Refers to the impact of a reduced ability to take in, understand and use healthcare information to make decisions and follow instructions for treatment on an individual's health status.

People with learning disabilities may have poor bodily awareness and a minority may have depressed pain responses. In addition, limited communication skills may reduce their capacity to convey identified health needs effectively to others (e.g., relatives, friends, paid support workers). As a result, carers (unpaid and paid) play an important role in the identification of health needs for many people with more severe learning disabilities. However, carers may have difficulty in recognizing expressions of need, or the experience of pain, particularly if the person concerned does not communicate verbally. Care workers may also feel that they do not have the knowledge, skills and training required to recognise emerging health problems or the resources to effectively promote health literacy.

People with learning disability express feelings of frustration that they are not listened to, are treated unfairly and excluded from decision making about important aspects of their lives and care.

Personal health behaviour and lifestyle risk determinants

Refers to personal health behaviour (including behaviours that challenge) and lifestyle risks such as diet, sexual health and exercise.

Diet

Less than 10% of adults with learning disabilities in supported accommodation eat a balanced diet, with an insufficient intake of fruit and vegetables. People with learning disabilities experience a lack of knowledge and choice in relation to healthy eating. Carers generally have a poor knowledge about public health recommendations on dietary intake.

Exercise

Over 80% of adults with learning disabilities engage in levels of physical activity below the Department of Health's minimum recommended level, a much lower level of physical activity than the general population (53%-64%). People with more severe learning disabilities and people living in more restrictive environments are at increased risk of inactivity.

Obesity & Underweight

People with learning disabilities are much more likely to be either underweight or obese than the general population. Women, people with Down's syndrome, people of higher ability and people living in less restrictive environments are at increased risk of obesity. The high level of overweight status amongst people with learning disabilities is likely to be associated with an increased risk of diabetes.

Substance Use

Fewer adults with learning disabilities who use learning disability services smoke tobacco or drink alcohol compared to the general population. However, rates of smoking are considerably higher among adolescents with mild learning disability and among people with learning disabilities who do not use learning disability services. People with learning disabilities with identified substance misuse were more likely to be male (61%) and to misuse alcohol.

Sexual Health

Little is known about inequalities in the sexual health status of people with learning disabilities in the UK. There is, however, evidence to suggest that they may face particular barriers in accessing sexual health services and the informal channels through which young people learn about sex and sexuality. A population-based study in the Netherlands reported that men with learning disabilities were eight times more likely to have sexually transmitted diseases. High rates of unsafe sexual practices have been reported among gay men with learning disabilities

Challenging behaviours

Severe self-injurious behaviours can result in damage to the person's health through secondary infections, malformation of the sites of repeated injury through the development of calcified haematomas, loss of sight or hearing, additional neurological impairments and even death. Serious aggression may result in significant injury to the person themselves as a result of the defensive or restraining action of others.

However, the health consequences of challenging behaviours go far beyond their immediate physical impact. Indeed, the combined responses of the public, carers, care staff and service agencies to people who show challenging behaviours may prove significantly more detrimental to their health and wellbeing than the immediate physical consequences of the challenging behaviours themselves. Social responses that are likely to have an adverse effect on health include abuse, inappropriate treatment, social exclusion, deprivation and systematic neglect.

- *Abuse*: Challenging behaviour has been identified as a major predictor of abuse in North American institutional settings. In the UK, recent analyses of the Count Me In Census indicated that in the previous three months 35% of people with learning disabilities in Assessment and Treatment Units had been assaulted, and 6% had been subject to 10 or more assaults.

- *Inappropriate Treatment*: Studies undertaken in North America and the UK suggest that approximately one in two people with severe intellectual disabilities who show challenging behaviours are prescribed long-term anti-psychotic medication. The widespread use of anti-psychotic medication raises a number of concerns as: (1) there is little evidence that anti-psychotics have any specific effect in reducing challenging behaviours; (2) such medication has a number of well documented serious side effects including weight gain and constipation; and (3) the use of anti-psychotics can be substantially reduced through peer review processes with no apparent negative effects for the majority of participants. The use of mechanical restraints and protective devices to manage self-injury also gives cause for serious concern. Such procedures can lead to muscular atrophy, demineralisation of bones and shortening of tendons as well as

resulting in other injuries during the process of the restraints being applied.

- *Social Exclusion, Deprivation and Systematic Neglect*: Challenging behaviours have been associated, among other factors, with families' decisions to seek an out-of-home residential placement for their son or daughter. Children and adults with challenging behaviours are significantly more likely to be excluded from community-based services and to be admitted, re-admitted to, or retained in more remote and more institutional settings. Within community-based settings, challenging behaviours may serve to limit the development of social relationships, reduce opportunities to participate in community-based activities and employment, and prevent access to health and social services.

Deficiencies in quality of and access to services determinants

Refers to the impact of services failing to take account of peoples' abilities and disabilities.

Organisational barriers

A range of organisational barriers to accessing healthcare and other services have been identified. These include:

- scarcity of appropriate services;
- physical barriers to access;
- eligibility criteria for accessing social care services;
- failure to make 'reasonable adjustments' in light of the literacy and communication difficulties experienced by many people with learning disabilities;
- variability in the availability of interpreters for people from minority ethnic communities;
- lack of expertise and disablist attitudes among healthcare staff;
- 'diagnostic overshadowing' (e.g. symptoms of physical ill health being mistakenly attributed to either a mental health/behavioural problem or as being inherent in the person's learning disabilities).

Consent

The National Patient Safety Agency has reported concern about 'consent being sought from a carer rather than taking the time to gain consent from the person with the learning disability'. In respect of the use of substitute (proxy) decision-making, one study of residential care found that whilst there was general compliance with the Mental Capacity Act (2005) in relation to larger strategic decisions, there was less compliance in respect of day-to-day decisions such as activity and food choices. A recent study in Wales of health care professionals and social workers, identified gaps in knowledge and training needs in relation to the Mental Capacity Act (2005). Similar findings were reported from a study of healthcare emergency workers in England.

Transition

Transition between services has been reported as problematic for some people with learning disability; this may for example include transition from children's services to adult services, but equally could be transition between hospital services and home or community services, or transitions from one phase of education to another. One study of teenagers' transitions through health, social care and education services found

weaknesses in transition planning, variable and mismatched eligibility criteria, lack of clarity from professionals and poor co-ordination between services together with low levels of satisfaction among family carers. A study of local authorities in Wales found that transition protocols for post-secondary education or employment were often vague with some lacking specific information about how young people would be involved and often failed to clarify the role of other agencies such as health services in these transitions.

Health Screening and Health Promotion

A number of studies have reported low uptake of health promotion or screening activities among people with learning disabilities. These include:

- Assessment for vision or hearing impairments;
- Routine dental care;
- Cervical smear tests;
- Breast self- examinations and mammography;

Access to health promotion may be significantly poorer for people with more severe learning disabilities and people with learning disabilities who do not use learning disability services. Staff in residential care homes had insufficient training and skills to effectively engage people with learning disabilities in health promotion activities and many did not have access to important relevant information such as a person's family history.

Primary and Secondary Health Care

People with learning disabilities visit their GP with similar frequency to the general population. However, given the evidence of greater health need it would be expected that people with learning disabilities should be accessing primary care services more frequently than the general population. For example, comparison of general practitioner consultation rates to those of patients with other chronic conditions suggests that primary care access rates for people with learning disabilities are lower than might be expected. In a recent study mean consultation rates for adults with learning disability were found to be lower than for the general population; increased age, female gender and having a paid carer were associated with greater use of GP services.

Collaboration between GPs, primary health care teams and specialist services for people with learning disabilities is generally regarded as poor. Adults aged over 60 with learning disabilities are less likely to receive a range of health services compared to younger adults with learning disabilities.

A number of papers draw attention to the benefits of health screening to help identify unmet health needs. The introduction of special health checks for people with learning disabilities has been shown to be effective in identifying unmet health needs, suggesting that health checks represent a 'reasonable adjustment' to the difficulties in identifying and/or communicating health need experienced by people with learning

disabilities. However, at present less than 50% of adults who are eligible for health checks under an incentivised Directed Enhanced Service scheme receive them. While providing financial incentives to GPs may influence practice, incentives should be tailored to the particular health needs of people with learning disabilities rather than being based solely on general population health needs. Furthermore GP practices may experience difficulties in accurately identifying people with learning disabilities in order to offer them health checks and other services.

People with learning disabilities have an increased uptake of medical and dental hospital services but a reduced uptake of surgical specialities compared to the general population. A recent study found that people with learning disability living in areas which had higher levels of deprivation made less use of secondary outpatient care but more use of accident and emergency care than those living in less deprived areas.

People with learning disabilities with cancer are less likely to be informed of their diagnosis and prognosis, be given pain relief, be involved in decisions about their care and are less likely to receive palliative care. Information and support such as that related to breast cancer and mammography may not meet the needs of some people with learning disability.

In one study nursing staff in UK general hospitals were found to have less positive feelings towards people with learning disability than people with physical disability.

Concern has been expressed with regard to the availability of and access to mental health services by people with learning disabilities. However, a very high proportion of people with learning disabilities are receiving prescribed psychotropic medication, most commonly anti-psychotic medication (40%-44% long-stay hospitals; 19%-32% community-based residential homes; 9%-10% family homes). Anti-psychotics are most commonly prescribed for challenging behaviours rather than schizophrenia, despite no evidence for their effectiveness in treating challenging behaviours and considerable evidence of harmful side-effects.

Non-health services

Wellbeing, health and quality of life are influenced by services other than health services including for example social care, education, employment, housing, transport and leisure services; this may be especially true for people with learning disabilities who may be regular users of these services. Evidence of how these services impact on the health of people with learning disabilities in the UK is scarce and researchers are faced with a number of methodological difficulties.

For example a recent literature review of supported housing found that smaller housing units had benefits in terms of choice, self-determination and participation but identified no measurable benefits for physical health.

Whilst another review found evidence of better quality of life for people living in dispersed rather than clustered housing.

Similarly there is little recent research into the link between social care services and the health of people with learning disabilities; for example one review found no research into the role of social care staff in initiating or supporting access to annual health checks.

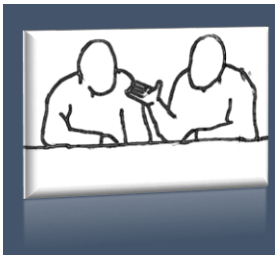
There is some recent evidence to suggest that supported employment can enhance the quality of life of some people with learning disabilities. However employment rates for people with learning disabilities in the UK remain low. Furthermore a study of people in Scotland drew attention to negative effects on people's psychological wellbeing resulting from the breakdown of supported employment which occurred in 13 of 49 people studied.

We are not aware of any recent UK research which specifically measures the impact of leisure services, travel services or education services on the health of people with learning disabilities.

Using the HEF+ to measure the impact of exposure to the determinants of health inequalities

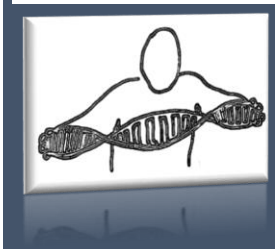
The *five determinants* of health inequalities are shown in figure 1 along with a series of *health inequality indicators* that were identified from the review of underpinning evidence.

Figure 1: Inequality indicators



Social determinants:

- Impoverished accommodation
- Lack of employment and meaningful activities
- Inadequate financial support
- Limited social contact
- Presence of additional marginalising factors
- Safeguarding issues



Genetic and biological determinants:

- Lack of assessment of health needs
- Lack of ongoing health needs reviews
- Poor quality health care plans / health action plans
- Absence of crisis / emergency planning & hospital passports
- Hazardous medication regimes and practice
- Unavailability of specialist service provision

Communication and health literacy:

- Poor bodily awareness and reduced pain responses
- Difficulty communicating with others
- Carers' failure to recognise pain / distress
- Carers inability to respond to emerging health problems
- Difficulties understanding health information and making choices

Personal health behaviour and lifestyle risks:

- Poor diet
- Inadequate exercise
- Difficulties maintaining a healthy weight
- Harmful patterns of substance use
- Hazardous sexual behaviours
- Other risky behaviours / routines

Deficiencies in access to, and quality of, health provision:

- Organisational barriers
- Failure to promote choice and seek consent
- Poor transition between services
- Lack of access to health screening / promotion
- Difficulties accessing mainstream primary / secondary services
- Difficulties accessing non-health, community resources

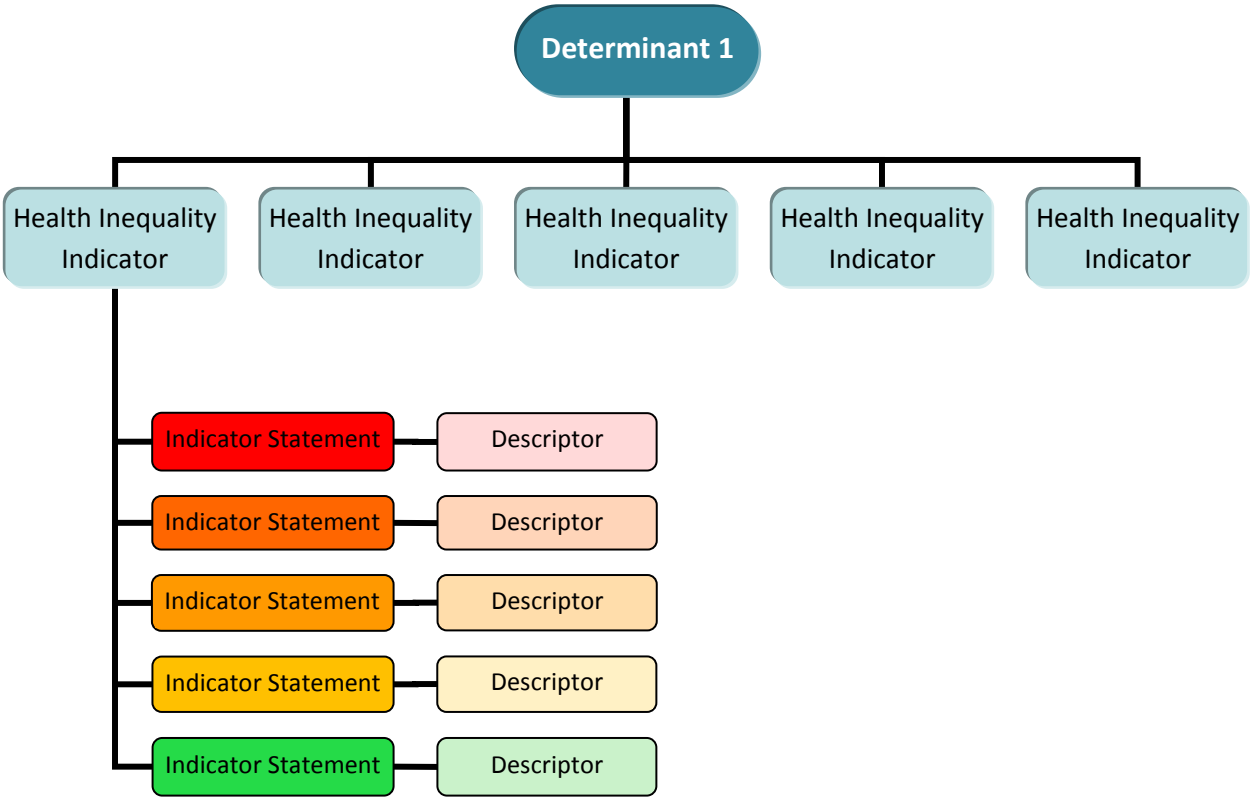
It is clear that continuing exposure to high impact ***health inequality indicators*** is predictive of a person experiencing serious health inequalities at some future point. The potential severity of the consequences in terms of outcomes is expressed as a series of ***impact levels*** below (based on the National Patient Safety Agency's risk matrix[10]):

Impact Level	Likely consequences if not addressed
Major	Health problems are associated with premature death. There may be multiple permanent injuries or irreversible significant long term health effects. Significant and prolonged restriction of normal activities and high risk of unplanned hospital admissions.
Significant	Major injuries and periods of ill health are likely, leading to long-term incapacity/disability and potential premature death. There may be prolonged periods of inability to engage in usual routines. May require complex and prolonged treatment. Likely to have recurrent unplanned hospital admissions.
Limited	Prone to moderate injury / illness requiring skilled professional intervention. Typified by recurrent breaks in engagement with normal routines. Recovery period following injury / illness several weeks longer than usual. Therapeutic intervention has significantly reduced in effectiveness.
Minimal	The person is likely to suffer minor injuries or illnesses which are likely to require minor intervention. There may be some intermittent short lived (i.e. a few days) impairment of engagement in usual activities. Recovery from periods of ill health may be slightly slower than would otherwise be the case.
No impact	Minimal impact requiring no/minimal intervention or treatment.

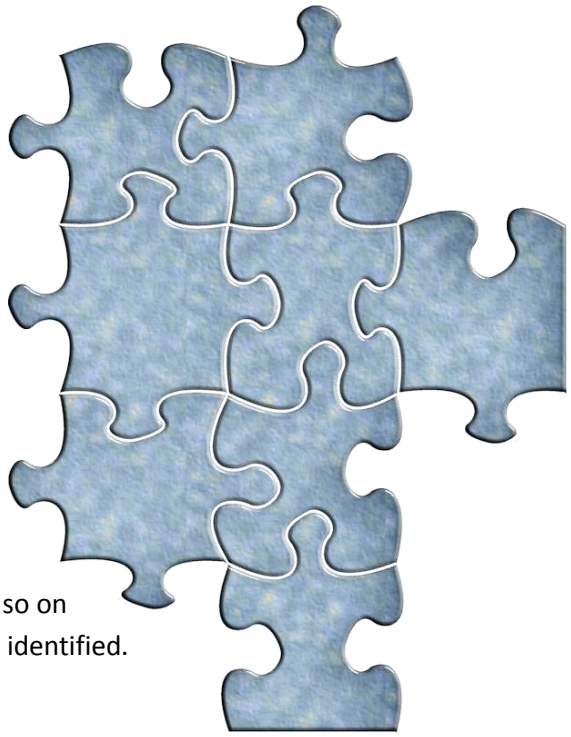
For each of twenty nine ***health inequality indicators*** that relate to the five determinants of health inequality, a series of ***indicator statements*** and ***descriptors*** were developed which relate directly each potential level of impact. These describe the circumstances of a person with a learning disability; the nature of their care and support; and what the services they receive might look like for each corresponding impact level.

[10] NPSA (2008) *Risk Matrix for Risk Managers*

The relationships between ***determinants***, ***health inequality indicators, indicator statements***, ***descriptors and impact levels*** is summarised below:



- There are five ***determinants***;
- The impact of exposure to each of these is measurable across a series of ***health inequality indicators***;
- Each of the health inequality indicators has a five point ***impact scale*** where ***indicators statements*** and more detailed ***descriptors*** provide the basis for practitioners to select the appropriate rating.



A Health Equalities Framework (HEF+) profile for an individual, is compiled by sequentially working through each of the ***health inequality indicators*** for each ***determinant*** and agreeing the appropriate ***impact rating*** at the time of profiling after considering the associated ***indicator statements*** and ***descriptors***.

Each ***health inequality indicator*** is given a rating between 0 and 4. Low scores indicate minimal adverse impact whereas high scores indicate a significantly detrimental impact.

For each ***health inequality indicator***, raters should begin by considering the ***indicator statement*** and ***descriptor*** associated with the highest (or most adverse) ***impact rating***. If this is not felt to be applicable they should then consider the next impact rating down, and so on until the one which best describes the person's current circumstance is identified.

When selecting the appropriate ***impact rating***, raters should be mindful that ***indicator statements*** and ***descriptors*** are composite in that they combine a number of aspects. ***Descriptors*** do not need to be met in full, if any aspect of a service user's current situation is consistent with any part of a ***descriptor*** then this is the correct ***impact rating.***

By working through the framework in this way the relative impact of each ***determinant*** can be established. The resulting data can be examined in more depth i.e. at a ***health inequality indicator*** level, in order to understand the greatest individual sources of exposure. This more detailed information can prove helpful when planning care and choosing appropriate targets for intervention.

This process establishes a baseline HEF+ profile for an individual. Outcomes are monitored through a programme of repeat profiling with individuals. This allows changes to be mapped over time. The effect of important events or changes such as moving house, bereavement, changes in employment or care and treatment can be tracked through such comparative profiling.

No paper based HEF+ recording sheet has been developed; data should be saved, collated and interpreted using the eHEF+ electronic interface. This freely available MS Excel spreadsheet has been specifically developed for this purpose and incorporates functions to allow aggregated data to be considered across caseloads, practitioners, teams or localities in order to inform the processes of service review, strategic planning and commissioning. Data can also be filtered in order to understand outcome variations across differing sub groups of people with learning disability (e.g. by severity of learning disability, according to additional disabilities or health conditions, age group, gender, ethnicity etc.).

It is for local providers and/or commissioners to decide how best to make use of the framework. Options include:

- For community teams profile at point of referral and discharge.
- HEF+ scores at the point of referral may provide a basis for triage assessment processes.
- Within community teams, HEF+ scores may form part of a caseload weighting process in order to inform allocations.
- HEF+ scores may be reviewed during CPA meetings, Health Action Plan reviews, Person Centred reviews etc.
- Within long term forms of service provision e.g. residential care homes or supported accommodation, routine HEF+ scoring may be useful at regular intervals e.g. every three months.
- HEF+ scoring prior to and post hospital stays is useful in establishing whether valid outcomes have been achieved.
- For practitioners who carry a caseload, HEF+ monitoring can inform prioritisation.
- Reviewing HEF+ profiles before and after specific interventions can inform an understanding of their effectiveness
- Individual caseload data can be aggregated and analysed.
- For managers of services, the ability to aggregate outcomes data across teams and practitioners can inform performance management.

- For strategic service planners (and commissioners) the ability to correlate HEF+ profiles against biographical details and specific profiles of service user need allows service improvements to be planned around local population profiles.
- Professional groups can use the profile to demonstrate the unique value of their contribution.

Indicators of exposure to determinants of health inequality

There follows a detailed breakdown of the Indicator Statements and Descriptors for each impact level for the Health Inequality Indicators associated with each of the determinants. (A summary of the indicators can be found in Appendix 1).

1. Social Indicators.

A. Accommodation

The quality of living standards for people with learning disabilities can vary widely. When considering accommodation it is important to consider the physical and the social environment. Risks may exist because of the physical environment (extreme damp, unsafe electrics, lack of adaptation around mobility problems etc.), or arise from the social environment (overcrowding, bullying, aggression from others, etc.).

Impact Level & Indicator Statement		Descriptor
4A	Accommodation presenting high risk, or in hospital / prison with no discharge accommodation identified or homeless	*The person has no settled accommodation. Accommodation arrangements are precarious, or the person has no, or low security of tenure / residence and so may be required to leave at very short notice. They may be in temporary short term accommodation with no appropriate move-on accommodation identified; or is in accommodation that is negatively impacting on their health and wellbeing. This includes people who are living in restrictive settings such as hospitals or prison. Problems with accommodation may have given rise to safeguarding concerns.*
3A	Inappropriate accommodation / accommodation at risk of breakdown	*The person lives in a setting which is not supportive of their identified health and social needs; or their accommodation is fragile and likely to be lost (e.g. due to negative relationships with peers / neighbours, lack of suitably skilled support, offending behaviour, or where notice has been served by the accommodation provider).*
2A	Shared accommodation with others / family – not by choice	*Accommodation is shared and was not of the person's choosing, or, if they lacked the ability to choose where to live, it was not identified following an appropriate best interest process. Alternatively the person may be living with their family, despite the fact that they or their family would prefer an alternative living arrangement that would give them more independence or support.*
1A	Settled single accommodation or shared with self-selected others	*The person lives in accommodation of their choosing (or if they lacked the capacity to make such a choice, an appropriate process was followed to determine it was in their best interests). They may be living on their own, or with others they have chosen to share with. However the accommodation may be in some form of registered care or where the person doesn't have full control over tenancy, care or support.*
0A	Settled family accommodation or own tenancy / ownership reflecting personal choice and control	*The person lives in settled accommodation of their own choosing, either with their family, or in an arrangement where they have security of tenure / residence over the medium to long term, as well as control over their care and support. (If the person lacked capacity to make a choice about where to live, it was identified following an appropriate 'best interests' decision making process).*

B. Employment, meaningful activities and engagement

Being engaged in meaningful activity is not dependent on degree of disability; it will be unique for everyone; and what is meaningful for one person may not be meaningful to another. Activity can range from different types of employment, education, training, home or community based activities, and these may be formal or informal. A good measure of meaningfulness is the degree of engagement in the activity. A meaningful activity for someone with profound intellectual and multiple learning disabilities may be massage, or listening to music, for more independent people it may be cooking or attending a club, for others it could be fulltime employment or attendance at a college course of their choice.

Impact Level & Indicator Statement		Descriptor
4B	No meaningful activities / engagement	*The person has no access to physical, social and leisure activities that are meaningful to them; or if activities are available the person does not (or is unable to) engage with them. They will likely be spending long periods of time with minimal stimulation or restricted engagement; or they may be engaging in activities chosen by others that are not meaningful to them. Problems with activities may have given rise to safeguarding concerns.*
3B	Highly restricted activity / engagement	*The person has extremely restricted access to meaningful activities, being available only for very short periods of time or very irregularly. It may be that it has been very difficult to identify / secure access to appropriate activities. Activities may only be provided within the person's home or there may be either no, or very restricted opportunities to access the wider community.*
2B	Limited meaningful activities / engagement	*The person engages in some activities that are meaningful to them; or, activities are identified and available but access to them is limited, inconsistent and/or unpredictable.*
1B	Voluntary work or other structured meaningful activity / engagement	*The person regularly accesses a range of available, meaningful, structured activities; this may be a combination of formal and informal activity. Or, for people who are able to work, may include opportunities to participate voluntary work.*
0B	In paid employment or education / fully, meaningfully engaged	*The person engages in a range of physical, social and leisure activities that are tailored to their needs and preferences. Such activities include paid employment or education of their choosing; and/or engagement in a range of meaningful activities across different environments and with different people.*

C. Financial support

The links between financial security and health are clear from the evidence. The majority of people with learning disabilities are in receipt of some sort of benefit, however sometimes there is a sense that finances are inadequate to meet an individual's needs. Material poverty can affect a person's ability to take a nutritious diet or to engage in activities within their community. Where entitlements are not taken up or monies are being held back by another party (see safeguarding) this can directly impact on an individual's health and well-being.

Impact Level & Indicator Statement		Descriptor
4c	Minimal or no financial support; or significant debts; or being financially abused.	*Here a person is either not in receipt of any, or has extremely limited financial support. This could be because of significant debts; financial exploitation by others; benefits not being claimed, or having been withdrawn, or being withheld. There may be serious safeguarding concerns in relation to finances.*
3c	Highly restricted access to adequate financial support and / or significant restrictions on spending decisions.	*The person has highly restricted financial support and/or significant restrictions of choice and control over how they spend their money (where the person lacks the ability to make their own decisions, no best interests process has been followed). This could also be because some benefits are not being claimed, or access to full entitlements is being restricted for some other reason.*
2c	Limited financial support with consequent restrictions on spending choices.	*The person's financial / material support is limited; there may be some restrictions on spending choices; or others may be controlling their financial resources. If the person has difficulties making choices about money - others may be making decisions without recourse to appropriate best interests decision making processes. This could include situations where a person does not meet eligibility criteria for a wider range of benefits; or could be limited because benefit payments only cover essential requirements.*
1c	Full financial support / benefits accessed allowing a reasonable quality of life.	*The person accesses their full benefit entitlement and this provides adequate financial support to allow them to enjoy a reasonable quality of life in accordance with their preferences.*
0c	Sufficient financial support to maintain good quality of life.	*The person has sufficient financial support and/or material resources to maintain a good quality of life, with finances being sufficient to support their choices, self-determination and to maintain their security.*

D. Social contact

Social contact can take many forms but is a clear indicator within quality of life measures and is essential for health and wellbeing. A strong social network will typically include family and friends though this may be disrupted due to remote and distant placements, lack of financial resource or availability of support. Other important social contacts may include neighbours, people with similar recreational interests or those with similar cultural backgrounds.

Impact Level & Indicator Statement		Descriptor
4D	Minimal or no appropriate social contact. Largely socially excluded / isolated.	*This level applies where there is very little, or no, appropriate social contact. This may mean that the person has been removed from societal contact and is socially isolated with little or no contact other than with paid workers and other users of the same service. It may also mean that social contacts are limited to individuals who are coercive and potentially abusive. There may be serious safeguarding concerns in relation to limited or existing social contact.*
3D	Fragile social networks.	*There are opportunities for the person to access appropriate social contact but it is fragile and/or is at risk of being lost. This may be for a wide range of reasons including behaviour, living situation, risk, staffing levels etc.*
2D	Social contact reliant on paid support or restricted.	*The person maintains some appropriate social contact but this is reliant on paid support. Alternatively, there may be restricted choice and control over social contact.*
1D	Access to some non-paid social networks.	*The person is able to maintain a range of appropriate social contacts independently, perhaps supported by the use of a personal budget. However such contacts may be limited (and this is not of the person's choosing) perhaps due to limited social networks, geographical remoteness, lack of access to alternative social media etc.*
0D	Engages with a wide range of established, non-paid social networks.	*The person has a wide range of appropriate social contacts and a well-established social network. The person is able to independently interact socially according to their own choices and preferences.*

E. Additional marginalising factors (such as ethnicity)

This indicator can cover a wide range of issues that can increase an individual's marginalisation. This can be linked to ethnicity, gender, behaviours, sexuality, appearance, physical features, chronic illness, speech differences etc.

Impact Level & Indicator Statement		Descriptor
4E	Marginalising factor(s) having major impact on, or leading to, a highly restricting lifestyle.	*Either one or more additional marginalising factors (over and above the person's learning disability) having major impact on the person's quality of life and/or safety; or a combination of several marginalising factors resulting in the person living a highly restricted lifestyle.*
3E	Additional marginalising factors present leading to isolation and having significant impact.	*Readily identifiable marginalising factors noted to be causing isolation and to be having significant impact on the person's freedoms, choices and quality of life with little support or action being taken to reduce their impact.*
2E	Some additional marginalising factors but impact on quality of life is minimal.	*Some identifiable marginalising factors (consider gender, age, sexual orientation, disability, ethnicity, religion, chronic illness etc.) over and above the person's learning disability but impact on quality of life is minimal given current support systems and within the person's current social / cultural context.*
1E	Minimal additional marginalising factors with no discernible impact; appropriate support is in place and effective.	*Minimal additional marginalising factors (consider the impact of gender, age, sexual orientation, disability, ethnicity, religion, chronic illness, occupation etc. in relation to the person's current cultural and societal context) over and above the person's learning disability. Any present have no discernible negative impact due to effective coping mechanisms; appropriate, effective and inclusive support (either formal or informal); or extensive engagement with a compatible peer group.*
0E	No additional marginalising factors over and above learning disability.	*No additional marginalising factors over and above the person's learning disability.*

F. Safeguarding

The inclusion of safeguarding issues within the framework enables the capture of any issues that may be impacting on the individuals' safety. Such factors may have been captured within another indicator (financial for example) however this indicator captures the formalisation of such risk areas including hate crime. It also includes issues related to the safety of others including children.

Impact Level & Indicator Statement		Descriptor
4F	Major concerns that abuse may be taking place.	*This level applies where there are current and major concerns that abuse may be taking place and there is currently no effective and agreed multi-agency plan by which to protect the person.*
3F	Significant concerns that the person is at risk of actual abuse.	*There is a high degree of concern that the person is at risk of actual abuse and a coordinated, multi-agency plan to reduce risks has been agreed, is being implemented and monitored. There may be additional indicators of possible ongoing abuse or risks to others that require monitoring; however recording, monitoring and transparency within support systems may be considered to be ineffective.*
2F	Some concerns that the person is at risk of abuse.	*There are indirect indicators or suspicions of risks of abuse that may impact on the person or others. This could be where the person is in shared accommodation where abuse (sexual, physical, psychological, domestic, discriminatory, financial, or neglect) of another individual has been identified. There may be cultural issues within the support environment or the person's social network which need to be addressed. There is a coordinated approach to monitoring the situation, sharing concerns and taking action to establish a protection plan.*
1F	Minimal safeguarding risks, though vulnerable.	*Potential threats to the person's wellbeing exceed their ability to cope with those threats - they are therefore vulnerable but the current risks to safety and wellbeing are minimal as a result of effective support, transparent recording and monitoring.*
0F	No safeguarding concerns.	*There are no current safeguarding concerns and any risks are minimal and well managed. The person (and / or those who care for and support them) has well established strategies by which to cope with potential future threats.*

2. Genetic and biological indicators.

A. Assessment of physical and mental health needs; and health checks

The assessment of physical and / or mental health needs can be complex. Many specific health conditions are considerably more prevalent in the learning disability population, epilepsy, respiratory conditions, and anxiety for example. There can be difficulties in detecting and recognising conditions and symptoms (often atypical) of specific health conditions. Understanding interactions between specific learning disability conditions and the environment also requires consideration. Annual Health checks can help to reduce some of these difficulties.

Impact Level & Indicator Statement		Descriptor
4A	Physical and/or mental health not assessed. Little or no understanding of needs.	*There has been no appropriate or effective assessment of needs; and/or no annual health check; and/or the person has had highly restricted access to health screening. The person may be experiencing regular serious untoward health incidents and unplanned hospital admissions with no consensus having been formed around the needs that are associated with these. Health problems may be seen as part of the learning disability (diagnostic overshadowing). There may be a lack of health surveillance for people who have problems communicating. There may be serious safeguarding concerns in relation to the assessment of health needs.*
3A	Assessment has commenced. Only superficial needs recognised. Ongoing delays due to multiple obstacles.	*This level applies where needs assessment has commenced but there are significant delays in completing it due to multiple obstacles, these might include difficulties accessing history, lack of physical examination and investigations. Only a superficial understanding of needs has been articulated. In the absence of a fuller understanding, the person may have continuing, occasional, unplanned hospital admissions.*
2A	Superficial assessment completed but delays accessing treatment or further assessment.	*A superficial assessment has been carried out but there are delays in accessing investigations or more specialist assessment without which full identification of needs, potential diagnosis and access to treatment are likely to be delayed. It is not possible to advance the assessment process in the absence of these investigations.*
1A	Assessment completed but not fully informed. Needs have been described.	*An assessment has been completed and a range of needs described however the assessment is based on a limited history; without being fully informed by all relevant investigations; in the absence of a full range of physical examinations; and/or without full input / consultation from clinicians with specialist knowledge related to the person's known health conditions; and/or where the person has been unable to consent to the assessment and it has been determined to be in their best interests, without appropriate consultation with family, advocate and/or carers.*
0A	Physical and/or mental health needs comprehensively assessed and fully understood.	*There has been a recent, comprehensive assessment of health and social care needs which included consideration of needs known to be specifically associated with the cause of the person's learning disability. There will have been an Annual Health Check (where the person is eligible for one) and the person will have accessed any relevant nationally available health screening programmes. The assessment will have been informed by consideration of the person's history, an appropriate range of investigations and discussion with the person, their family, carers or advocates as appropriate. The views of any appropriate specialist clinicians will have been taken into account.*

B. Planned reviews of need

Many people with learning disabilities have long term conditions, however the established pathways for the treatment of such conditions (dementia, epilepsy, diabetes etc.) are not always provided. People's needs change over time and therefore require regular review. Some people with learning disabilities can continue to receive treatments that are no longer appropriate or required.

Impact Level & Indicator Statement		Descriptor
4B	No effective ongoing review mechanisms.	*The person has needs requiring specific actions but no care plans are in place. As such there is no mechanism by which to review and evaluate the effectiveness of care and support given and the person may not be getting adequate support with their health needs. There may be serious safeguarding concerns in relation to care planning.*
3B	Inadequate arrangements for reviews.	*Some care plans are in place to address specific known conditions however care plans are not reviewed by people competent to do so; or are reviewed according to an administrative cycle rather than in response to changes in presentation; there may be an absence of objective measures by which to review plans; and there may be differing views / disagreement regarding the effectiveness of current plans.*
2B	Care plans reviewed but not inclusive of all relevant parties.	*Care plans are regularly reviewed according to a predictable cycle. Reviews are undertaken by a single practitioner without appropriate liaison with the person, family, advocate and/or carers. It is apparent that reviews commonly lead to revision and refinement of care plans.*
1B	Regular, effective, appropriate and responsive reviews undertaken.	*There are known assessed needs for which specific care plans exist. The care plans are regularly and effectively reviewed by a person / team with the necessary knowledge and skills to evaluate them; this is done in consultation with the person, their advocates, families and carers as appropriate. In addition to regular review cycles there are also responsive reviews when health needs or status changes.*
0B	No significant health needs, review not required.	*This level applies where there is no requirement for care plans as a full and thorough assessment has not identified any significant health needs and the person has easy access to primary healthcare services should they be needed.*

C. Care Planning / health action planning

Care planning is the means by which care needs are identified. The care plan is an important focus for good communication; it should guide the work of others and be a basis for continuity of care. Health Action Plans identify what needs to happen and who needs to do it. There can be difficulties if these plans are unclear, inadequate, misleading, contradictory or not acted on appropriately.

Impact Level & Indicator Statement		Descriptor
4c	No Care plans / Health Action plans in place.	*This level applies where the person has needs requiring specific actions but no care plans are in place. This means that the person is not getting adequate support with their health needs and the lack of planning could result in serious ill health; there may be serious safeguarding concerns in relation to lack of care planning.*
3c	Non condition specific care plans / Health Action Plans in place (not in accordance with evidence base e.g. NICE guidance).	*This level applies where a person has care plans in place but they do not adequately address the specific conditions that are known to exist. For example someone with Down's syndrome who does not have thyroid function testing identified in their care planning, or someone with epilepsy who does not have a care plan for the management of seizures that is in line with best practice recommendations (e.g. NICE guidance). Alternatively it may be that those implementing care plans lack the skills to effectively do so.*
2c	Condition specific, generic care plans / Health Action Plans in place. Plans may be incomplete.	*This level applies where care plans are in place to address specific known conditions; however the plans may be generic; and not individualised or person centred. Plans may be incomplete in that they do not adequately meet all areas of need, or cover anticipatory healthcare needs or health promotion; or include monitoring of indicators of efficacy.*
1c	Condition specific person centred care plans and Health Action Plans in place.	*There are some known needs for which specific care plans exist. These may form part of a Health Action Plan, or may constitute a more detailed plan of specific care and treatment for a particular issue. Plans are in keeping with current evidence and are based around the specific needs of the person in a personalised way. Care plans address presenting health needs, anticipatory healthcare needs and health promotion. Clear measures of effectiveness are incorporated.*
0c	No care plans or Health Action Plans required.	*This level applies where there is no requirement for planned care as a full and thorough assessment has not identified significant needs. The person has ready access to primary care as and when needed. Health Action Plans provide a record of current health status.*

D. Crisis / emergency planning and hospital passports

Emergency plans can prevent a lot of the difficulties associated with a crisis or urgent admission to hospital. They are only effective if they are regularly reviewed and updated and they focus on the specific needs of the individual, are person centred and take account of local circumstances. Hospital passports help to ensure that an individual's needs are met if and when they need to be admitted or if they require hospital treatment or assessment.

Impact Level & Indicator Statement		Descriptor
4D	Despite clear evidence of need, no crisis, emergency or relapse plans; or hospital passport (where appropriate) in place.	*This level applies where there are no plans to respond to a crisis of health need. A hospital passport has not been completed. There may be serious safeguarding concerns in relation to crisis or emergency planning.*
3D	Crisis / emergency / relapse plans and hospital passport inadequate, not person centred or reviewed; or consistently not utilised.	*Crisis and/or emergency plans, and a hospital passport have been completed but are inadequate, incomplete or out of date; this may be because they are not person centred, not robust or fit for purpose. Or, it may be that those providing care and support consistently fail to make use of these plans in support of health related appointments and hospital attendances.*
2D	Crisis / emergency /relapse plans and hospital passport as appropriate in place, not reviewed or occasionally not utilised.	*Crisis and/or emergency plans, and a hospital passport are person centred but have not been reviewed. There may be occasions where those providing care and support fail to routinely take hospital passports (or equivalent) when attending hospital or other health appointments.*
1D	Crisis / emergency /relapse plans and hospital passport in place as appropriate, are person centred, routinely used and reviewed.	*Crisis, emergency and, where appropriate, relapse plans and a hospital passport are all in place. These plans are person centred, individualised, up to date and regularly reviewed.*
0D	No crisis / emergency plans required, appropriate person centred information in place.	*This level applies where a person does not require any emergency or crisis plans; they are likely to have good networks of support and good communication. Where appropriate a hospital/communication passport is complete, person centred and up to date.*

E. Medication

Due to increased co-morbidity, people with learning disabilities often take multiple medications giving rise to complex interactions. In some instances they are more prone to adverse and atypical effects of medications and yet may have difficulty reporting side effects which are hazardous to health and wellbeing. People who present challenging behaviour may be subjected to unlicensed prescribing of anti-psychotics. On occasion people may require covert administration of medication; this should always be subject to appropriate capacity assessment and best interest processes.

Impact Level & Indicator Statement		Descriptor
4E	Unlicensed / contraindicated use of medication. Extremely hazardous medication regime. Or, administration errors.	*Medication is being used that is not in keeping with the individual's identified needs e.g. not prescribed for a diagnosed and/or licensed use, or in excess of recommended dose limits. Medication recommended for short term use may have been taken for prolonged periods without regular review (e.g. benzodiazepine anxiolytics, prophylactic antibiotics); or medication which has hazardous side effects and a narrow therapeutic window. There may be frequent medication administration errors without subsequent action to prevent recurrences. There may be serious safeguarding concerns in relation to medication.*
3E	Potentially hazardous medication regime without adequate reviews and monitoring. Significant compliance issues.	*Despite significant poly-pharmacy, or high dosages, medication continues to be administered without routine specialist reviews; and the effectiveness or side effects are not being adequately monitored. Medications may be known to have especially hazardous side effects which are not readily apparent without specialist knowledge or vigilant monitoring. Those providing support are not managing medication appropriately; there are significant problems with compliance.*
2E	Medication reviewed but not regularly monitored; maybe with inconsistent use of 'as required' medication.	*Medication may be being reviewed (perhaps annually) but there is poor on-going monitoring of effectiveness and/or side effects. Those providing support are not monitoring or recording medication effectively or there may be occasional issues / problems with compliance. There may be inconsistencies in the use of 'as and when required' medication.*
1E	Small amount of medication, regularly reviewed and effectively monitored.	*The person takes a small number of medications (including prescribed dietary supplements and artificial feeds) which have readily discernible side effect profiles. In the case of 'as and when required' medications, the prescriber has clearly described under what circumstances they should be taken, as well as any required precautions. The therapeutic and adverse effects of medication are carefully monitored and recorded by those providing care and support, with regular and appropriate reviews. There are minimal problems with compliance. Medication is all within BNF limits and prescribed for indicated uses only. Medication is administered safely and appropriately.*
0E	No medication.	*This level applies where there is no current medication required.*

F. Specialist learning disability service provision

This indicator relates to the access and quality of specialist learning disability services (e.g. community learning disability nursing, speech and language therapy or psychology services) and their ability to provide a level of support that meets an individual's specialist health needs that would otherwise not be met in a mainstream setting alone.

Impact Level & Indicator Statement		Descriptor
4F	No specialist learning disability service provision available.	*A specialist learning disability service is not available to an individual. This may be because there is a lack of specialist service provision locally or that access is being denied or withheld. There may be serious safeguarding concerns in relation to the lack of appropriate specialist service provision.*
3F	Restricted specialist learning disability services available, not able to meet all identified needs.	*Some specialist learning disability services are available but access may be restricted by referral criteria or pathways; delayed due to prolonged waiting times; or some key elements (therapies or therapists) may not be available; or some elements are not available locally. There may be a lack of support to access the service available. There may be areas of identified need that cannot be met.*
2F	Limited specialist learning disability service available.	*A limited specialist learning disability service is available locally and is being provided but there may be limitations in terms of the capacity, responsiveness, consistency, quality or scope of the service available. There may be limited support to access the service.*
1F	Full specialist learning disability service available and accessed in accordance with identified needs.	*A full high quality specialist learning disability service is available and is being accessed by the person in accordance with their assessed needs and care plans. There is adequate support to access the service but there may be short delays in timely response to referral.*
0F	Full specialist learning disability service available but not currently required.	*A full, high quality and appropriate specialist learning disability service is accessible and available but not currently required. As a minimum, such services will include learning disability nurses, psychiatrists, psychologists, occupational therapists, physiotherapists and speech and language therapists. There will be transparent referral pathways and timely responses.*

3. Communication difficulties and reduced health literacy indicators.

A. Poor bodily awareness, reduced pain responses and communication support

The ability of individuals to recognise normal and abnormal bodily sensations including pain can vary. Some people may be at serious risk because of their inability to express themselves effectively and the inability of others to understand / or respond appropriately. Some people present behaviours described as challenging in response to pain.

Impact Level & Indicator Statement		Descriptor
4A	Major restrictions of bodily awareness, pain responses. Needs very difficult to discern.	*This level applies where a person is completely unable to recognise abnormal body sensations and is able to show little or no discernible response to pain; they receive no appropriate support with identifying needs. There may be serious safeguarding concerns in relation to body awareness, pain responses and communication support.*
3A	Significant restrictions of bodily awareness and pain responses and inadequate support to identify needs.	*The person is significantly restricted in their capacity to recognise abnormal body sensations and signs of ill health including pain and distress; receives inadequate appropriate support with identifying needs.*
2A	Some restrictions of bodily awareness and pain responses with limited support to recognise needs.	*The person has some limitations in recognising abnormal body sensations and signs of ill health, including pain. They receive limited support from others with identifying needs.*
1A	Some restrictions of bodily awareness and pain responses but appropriate support to help identify needs.	*The person has some limitations in terms of their body awareness and their ability to recognise signs of ill health but shows largely normal responses to pain / distress. They receive appropriate support with identifying needs.*
0A	No identified difficulties with bodily awareness and pain responses.	*The person has good body awareness, recognises signs that could indicate ill health and shows normal adaptive responses to pain / distress.*

B. Communicating health needs to others

People with learning disabilities have varying ability to communicate their health issues to others. Those offering support may miss the significance of behavioural indicators of pain / discomfort / distress.

Impact Level & Indicator Statement		Descriptor
4B	Major restrictions to person's ability to communicate about their health. No support in place.	*There are major difficulties, as a result of highly complex needs in relation to a person's communication, such that the person is completely unable to communicate in a way that others recognise. There may be no support /or resources to aid communication of health needs; or where these exist, they make little difference. There may be serious safeguarding concerns in relation to communication of health needs. Non-verbal indicators of pain / distress are extremely difficult to discern.*
3B	Despite support, there are significant restrictions to person's ability to communicate with others regarding their health.	*There are significant difficulties as a result of complex needs and an extremely limited ability to effectively communicate information about their health experiences to others. The support they receive is relatively ineffective in enabling them to adequately communicate health needs. Those who know the person best may recognise important subtle communications both verbal and non-verbal but these are not always acted on.*
2B	Notable restrictions with the person's ability to communicate about their health.	*There are some difficulties as a result of complex needs and the person's limited verbal communication. This impacts significantly when the person attempts to communicate about complex and highly subjective health related experiences. They may be heavily reliant on appropriate support from people who know them well, as well as the use of customised communication tools / aids.*
1B	Minimal restrictions with the person's ability to communicate about their health with others but appropriate support in place.	*There are minimal difficulties as a result of a person's ability to communicate with others. The person may struggle to communicate some aspects or detail of their health issues but they have appropriate support and resources to aid communication.*
0B	No identified restrictions with the person's ability to communicate about their health.	*There are no identified difficulties related to the person's ability to communicate with others. They can articulately describe their signs, symptoms, health history, concerns and health needs to others.*

C. Carers ability to recognise expressions of needs / pain

It is important that people providing care or support, have access to training or support about communication and the identification and management of pain, illness and distress.

Impact Level & Indicator Statement		Descriptor
4c	Major difficulties with the ability of those providing support to recognise pain / distress.	*This level applies where there are major health risks associated with a failure on the part of those providing care and support to recognise pain, distress or ill health resulting in a significant deterioration of physical and/or mental health and wellbeing. There may be serious safeguarding concerns relating to the recognition of needs / pain.*
3c	Significant difficulties with the ability of those providing support to recognise pain / distress.	*There are significant difficulties associated with the failure of those providing care and support to recognise signs of pain, distress or potentially serious ill health (physical and/or mental). This may have resulted in failure to access early treatment, episodes of serious ill health or hospital admissions. Those providing support have received little if any training around the health needs of people with learning disability.*
2c	Consistent difficulties with the ability of those providing support to recognise pain / distress.	*There are consistent minor difficulties associated with the ability of those providing care and support to recognise signs of potential ill health (physical and/or mental). This may include inconsistent recognition and treatment of pain and distress; and an inability to use bespoke pain recognition tools. Those providing support have received only basic training around the health needs of people with learning disabilities.*
1c	Occasional difficulties with the ability of those providing support to recognise pain / distress.	*There are occasional difficulties in terms of recognising potential ill health (physical and/or mental), on the part of those providing care and support. It may be that just a few people who provide support may know the person well enough recognise potential distress (e.g. families). There may be occasional misinterpretations or failures to recognise or appreciate the significance of signs and symptoms indicating pain, distress or ill health insofar as they relate to relatively minor health conditions. Paid carers providing support have received training specifically relating to the health needs of people with learning disabilities.*
0c	No identified restrictions with the ability of those providing support to recognise pain / distress.	*There are no identified difficulties associated with the ability of those who provide care and support to recognise signs and symptoms (or expressions) indicating pain, distress or ill health (physical and/or mental). They may be proficient in using bespoke, individualised pain recognition tools that are not dependent on the person having advanced verbal communication skills.*

D. Carers ability to respond to emerging health problems and / or promote health literacy

People with learning disabilities can present atypically in response to changing health status. There may be behavioural or emotional changes to pain or distress. People may lack the cognitive or communicative skills to describe their experiences, understand the nature of their condition or the importance of adherent to treatment plans. There may be a degree of dependence on carers to make informed and timely responses to evidence of ill health before conditions become more serious.

Impact Level & Indicator Statement		descriptor
4D	Major difficulties related to the ability of those providing support to respond to emerging health problems.	*This level applies where there are major difficulties resulting from the failure of people who provide care or support to respond appropriately and promptly to signs of seriously ill health (physical and/or mental). There may be serious safeguarding concerns relating to carers abilities in this area.*
3D	Significant difficulties related to the ability of those providing support to respond to health problems.	*This level applies where there are significant difficulties arising from the inability of those who provide care or support to respond to signs of ill health (physical and/or mental). Despite signs of ill health being recognised by carers, it may be that their potential seriousness is not; and that consequently prompt and urgent responses fail to occur. Alternatively appropriate responses may be inhibited due to service issues, information or knowledge issues, language, cultural issues; or the person or their carer's values, beliefs, attitudes and preferences.*
2D	Consistent difficulties related to the ability of those providing support to respond to emerging health problems.	*There are consistent minor difficulties resulting from difficulties of those providing support in responding to emerging health problems (physical and/or mental). It may be that they fail to follow advice or previously agreed crisis plans, or that they delay before instigating them. They may not know how to access additional support or approach the wrong agencies. There may be a lack of clarity around their role, difficulties prioritising appropriately, or concerns about approaching professionals. There may also be failings to provide appropriate support and reassurances to the person concerned.*
1D	Occasional concerns related to the ability of those providing support to respond appropriately to emerging health problems.	*There are occasional difficulties relating to the ability of those who provide care or support to respond to emerging health problems (physical and/or mental). Although there may be occasional lapses, they largely know who to contact, do so in a timely manner, maintain good observations and relay critical health related information to inform further health needs assessment. They also offer basic reassurance and advice to the person, using appropriately modified communication.*
0D	No identified concerns regarding the ability of those providing support to respond to emerging health problems.	*There are no identified difficulties related to the ability of people who provide care or support to respond appropriately and promptly to emerging health problems (physical and/or mental). Hospital passports and Health Action Plans have been established and guide responses to changes in health status.*

E. Understanding Health Information and Making Choices

People who have learning disabilities often have difficulty understanding health information this can affect their ability to make informed choices. It is essential that people are empowered wherever possible to make choices based on information that is designed to meet their needs.

Impact Level & Indicator Statement		Descriptor
4E	Major restrictions related to the person's capacity to access and understand health information and make choices.	*There are major difficulties resulting from a person's complete lack of understanding and awareness of health information. This threatens to undermine the success of treatment and care plans. There is little or no support that can increase understanding or involvement and the person (or those who know them best) is excluded from decisions relating to their own health and wellbeing. There may be serious safeguarding concerns relating to understanding health information and making choices.*
3E	Significant restrictions related to the person's ability to access and understand health information.	*There are significant difficulties' resulting from a highly restricted understanding and awareness of health issues and information. There is limited support to enable the person to make their own decisions (and limited inclusion in this process of those who know them best) in relation to health and wellbeing; support available is only partially effective. Basic information is used to help the person anticipate and cope with health related procedures although for many areas of decision making a suitable best interests' decision making process is not being followed.*
2E	Consistent difficulties related to the person's ability to access and understand health information and make choices. With good support can make some decisions.	*There are consistent minor difficulties resulting from a person's restricted awareness of health issues and lack of understanding of health information. The use of modified communication and literature as well as the support of skilled communicators who know the person well, improves understanding, leading to increased involvement in decision making and encourages a healthier lifestyle.*
1E	Some restrictions related to the person's ability access and understand health information but with good support they are able to make choices.	*There are occasional difficulties resulting from a person's lack of awareness of health issues and/or problems understanding health related information. This may cause problems in terms of understanding the need to take treatments, to maintain a healthy lifestyle and to make informed choices. With good support and the use of accessible information in accordance with the person's needs they can however be fully included in making choices about their health.*
0E	No identified restrictions related to the person's ability to access and understand health information and to make choices on the basis of these.	*There are no identified difficulties related to an individual's understanding and awareness of health information and they are fully involved in planning for good health.*

4 Personal behaviour and lifestyle indicators.

A. Diet and hydration

People with learning disabilities commonly take poor diets. In some instances, due to reduced health literacy, they have a poor understanding of what a healthy diet is. Other people are dependent on carer knowledge to ensure they receive a balanced and nutritious diet. Some people risk health complications associated with excessive or restricted fluid intake. People may have specific dietary requirements due to other health conditions, or medication side effects. Given the high incidence of swallowing difficulties, some people require food and drinks to be of a modified safe consistency.

Impact Level & Indicator Statement		Descriptor
4A	Major concerns about eating and drinking which place the person's safety and well-being at imminent risk.	*The person has known swallowing difficulties but does not have consistency of food modified. Or takes little or no food or fluid without considerable encouragement which is not readily available. Or eats hazardous (otherwise inedible) items with no restrictions. Or eats foods hazardous to known health status e.g. high sugar foods if diabetic, or foods contraindicated by medication with no support to modify. Or there are serious safeguarding concerns.*
3A	Restrictions to healthy eating and drinking which compromise the person's long term safety and wellbeing. Little support to address these issues.	*Food consistency is not wholly safe; or fluid intake is excessive or minimal. Or diet has a complete omission of one or more essential component (e.g. fruit, veg or dairy products); or an extreme excess of an unhealthy constituent of food (e.g. salt, sugar or saturated fat etc.); or wholly inadequate calorific intake. With little support to modify. Amount of food taken is a significant concern.*
2A	Some notable difficulties maintaining healthy eating and drinking. Some support in place to address these.	*The person takes a mix of grain based foods, milk, meat, veg and fruit though widely discrepant from normal recommended daily amounts – some support to address these issues and support healthy intake. If food consistency is an issue there may be occasional lapses of stringency in support.*
1A	Relatively minimal restrictions to healthy eating and drinking.	*The person takes adequate food and fluid of safe and appropriate consistency. There may be relative excesses or limitations of some key areas of nutritional intake. Meals may lack variety or have modestly excessive salt or sugar content. Support is available to address known issues.*
0A	No restrictions to healthy eating and drinking.	*The person takes a healthy balanced diet consistent with their needs and prepared in a manner which can be taken without risk, including supported feeding systems. They take 6-8 glasses of water (or other fluids or prescribed hydration through supported feeding) per day and carers are well informed and provide support regarding public health recommendations on healthy eating.*

B. Exercise

People with learning disabilities often lead a more sedentary lifestyle than non-disabled peers. There may be issues of motivation or inadequate levels of support to allow engagement in exercise. Some people have extremely complex physical disabilities that mean traditional activities by way of exercise are difficult to engage in. Exercise can be a 'lifestyle activity' (in other words, walking to the shops or taking the dog out) or structured exercise or sport, or a combination of these; it does need to be of at least moderate intensity, measured by it making the person slightly breathless or a little warm.

Impact Level & Indicator Statement		Descriptor
4B	Major restrictions related to appropriate physical activity / exercise putting safety and well-being at risk.	*The person takes little or no exercise of an even mild intensity, appropriate to age and health condition. May be immobile or just sedately mobilising around living environment. Poses risks to skin integrity, cardiovascular system, bones and joints. Alternatively may undertake high intensity, vigorous activity despite significant underlying medical conditions which mean excessive cardio vascular work load should be avoided. No appropriate support with exercise in place. There may be serious safeguarding concerns in relation to exercise.*
3B	Significant lack of engagement in physical activity / exercise.	*The person takes little or no moderately vigorous exercise; or undertakes energetic activity, appropriate to age and health condition for brief periods only, no more than once or twice a week. Restricted access to support, understanding in relation to exercise of those providing support is minimal.*
2B	Some restrictions engaging in healthy regime of physical activity / exercise.	*The person takes less than a weekly total of an hour and a half of moderately vigorous activity, appropriate to age and health condition. Takes such exercise on less than four days per week. Support available but not appropriately implemented or utilised.*
1B	Few concerns related to the person's engagement in physical activity / exercise.	*The person undertakes moderate intensity activity on four or five days per week, or for less than 30 minutes in a day, appropriate to age and health condition. Appropriate support and encouragement is provided.*
0B	No restrictions related to engaging in healthy regime of physical activity / exercise.	*The person takes a degree of exercise of a nature and quantity appropriate to age and general health condition. A mixture of aerobic and muscle strengthening activities on five or more days per week. No support required.*

C. Weight

People with learning disabilities are prone to being either overweight or underweight. Obesity brings a whole range of risks in its own right and can also increase the hazardous nature of exposure to other determinants of health in (e.g. genetic cardio vascular problems or hazardous medications). Being underweight or malnourished increases risk of serious medical complications including recurrent infection and impaired renal function.

Impact Level & Indicator Statement		Descriptor
4c	Major concerns about the person's ability to achieve / maintain an appropriate weight, placing them at risk of serious health problems.	*BMI is less than 15 or over 40. Or there is unplanned loss of more than 10% weight over 3-6 months. No support available to achieve or maintain appropriate weight. There may be serious safeguarding concerns in relation to weight.*
3c	Significant difficulties achieving / maintaining appropriate weight.	*BMI is 15-16; OR BMI 35-40. Or there is unplanned loss of 5-10% weight over 3-6 months. Restricted access to support to achieve or maintain appropriate weight.*
2c	Notable difficulties / restrictions on ability to achieve / maintain an appropriate weight.	*BMI is 16-18.5; OR BMI is 30-35. Or there is unplanned loss of less than 5% weight over 3-6 months. Support available but not appropriately implemented or utilised to achieve or maintain appropriate weight.*
1c	Some difficulties achieving / maintaining an appropriate weight.	*BMI is 25-30. Weight is stable. Appropriate support and encouragement is provided to achieve or maintain appropriate weight.*
0c	No difficulties maintaining appropriate weight.	*BMI is 18.-25. Weight is stable. No support is required to achieve or maintain appropriate weight.*

D. Substance Use

Vulnerable people can be become engaged in the harmful use of alcohol, smoking and non-prescription drugs and other harmful substances. This can make them particularly vulnerable to exploitation and may result in problems with relationships, finances and offending behaviour. They may find it difficult, or be reluctant to engage with activities to change their behaviours. Some people may have developed ritualised behaviours or be dependent on routine.

In addition people often need support from others, who may not be well informed about the harmful impact of alcohol, smoking and other dangerous substances, or skilled in supporting and managing risky behaviours.

Impact Level & Indicator Statement		Descriptor
4D	Dependence on drugs, alcohol, or other harmful substances.	*There is evidence of a strong compulsion to take the desired substance, where a withdrawal state is associated with abstinence. There may be evidence of tolerance (indicated by increasing quantities of the desired substance being required to achieve the desired effect). Alternative pleasures are neglected. No support or access to services in place. There are serious safeguarding concerns in relation to substance use.*
3D	Harmful use of drugs, alcohol, tobacco or other substances.	*There is an evident pattern of substance use which has significantly contributed to physical, psychological or social harm. Limited support or access to services.*
2D	Hazardous use of drugs alcohol, tobacco or other recreational drugs but no evidence of actual harm at this stage.	*Consumption is at a level associated with a significantly increased risk of harm, albeit that there is currently no evidence of actual harm. Or there is a minimal level of recreational drug use. Some support provided.*
1D	Largely safe use of alcohol. No use of recreational drugs.	*There is evidence of some risky behaviour in relation to the use of alcohol. Behaviours demonstrated are considered to pose a limited risk to the person's health and wellbeing with potential for morbidity. E.g. where the person generally keeps alcohol consumption to a safe level, but occasionally drinks an excessive amount. Support available if needed.*
0D	No harmful use of alcohol. No use of other substances.	*There is no use of substances other than alcohol and drinking is within Public Health recommended safe limits. (Or there is no use of alcohol). Consumption poses a minimal risk to health and wellbeing. E.g. Where the person consumes alcohol regularly but the amount is considered acceptable (Per week: at least two alcohol-free days, Men: no more than 21 units & no more than four units a day, Women: no more than 14 units & no more than three units a day).*

E. Sexual Health

Many people with learning disabilities engage in appropriate and healthy sexual acts and relationships. If they do this without having accessed sexual health services / education this may place their health at risk. Others are vulnerable and at risk of exploitation or given a lack of appropriate role models may engage in behaviours that are considered to be sexually unusual or unsafe (if not illegal).

Impact Level & Indicator Statement		Descriptor
4E	Very high risk sexual behaviours (may be consensual or not). Sexual abuse or sexual offending.	*In an abusive / exploitative sexual relationship. Or engages in sexual offending behaviour. Or has unprotected sex with people who are at high risk for sexually transmitted disease. No support provided. There are serious safeguarding concerns in relation to sexual health.*
3E	Unsafe and risky sexual behaviours (may be consensual or not).	*Has frequent unprotected sex of a nature that is hazardous to health, poses serious safeguarding issues or is illegal. Or has been exposed to sexually inappropriate role models. Or has had (and failed to detect) chronic sexually transmitted disease. Restricted support provided or limited access to services.*
2E	Inappropriate sexual behaviours (may be consensual or not) increasing vulnerability.	*Has limited awareness of sexual rights / norms though is sexually active. Has limited access to sexual health services. Limited understanding of what constitutes safe sex. Has had a lack of sexually positive role models. Lives in an environment where others display sexually inappropriate behaviours. Sexually active but not using contraception. Some support provided.*
1E	Healthy (consensual) sexual behaviours. Sexually isolated.	*Healthy sexual behaviours. May be interested in sex, though is sexually isolated. Has accessed contraceptive advice both to avoid pregnancy and the risk of sexually transmitted diseases. Appropriate support provided.*
0E	No hazardous sexual behaviours.	*Does not to engage in sexual activity (by choice in the case of people with capacity). Easy access to sexual health screening services.*

F. Risky Behaviour / Routines

Presentations of behaviours that may be described as 'challenging' may increase the risk of poor health. Such behaviours include aggression, self-injury, destructive behaviours and other difficult or disruptive behaviours. In some instances this latter category may include people who have rigid and fixed routines / habits of such intensity that they prevent the person from engaging in positive health behaviours or make accessing health services very difficult without well thought out reasonable adjustments. Clearly self-injury carries such risks as may the application of restrictive interventions. Consequences of such behaviours carry a risk greater exposure to abuse, inappropriate treatments, social exclusion, deprivation and neglect; each of these can have significant additional negative impacts. People who present such behaviours may be at heightened risk of such behaviours being viewed as being inevitably associated with their learning disability rather than indicative of poor health.

Impact Level & Indicator Statement		Descriptor
4F	Major health implications related to presentation of severe behavioural disturbance.	*The person presents behaviours which are of a frequency, severity or intensity that there is a high risk that either they or someone else will require unplanned hospital attendances due to severe injury. Or the person's behaviours mean they have no access to usual health provision. Or the person's situation is such that they are exposed to abusive contingencies. The factors that predict the occurrence or, and maintain behaviours are unknown.*
3F	Behaviours / routines have significant impact on health status.	*The person presents behaviours for reasons which are poorly understood; which mean that either they, or someone else, commonly requires first aid or occasionally suffers more serious illness / injury which requires medical attention. There may be occasional dramatic escalations in the severity / frequency of behaviours of concern. In an attempt to manage risks the person may be subjected to restrictive environment or hazardous treatments.*
2F	Behaviours / routines have notable impact on health.	*The person presents with a range of behaviours of concern. Causative factors have been partially assessed and are partly understood. Access to routine healthcare provision may be difficult to arrange or investigations not pursued as not perceived to be in the person's best interests. The impact of behaviours is relatively stable and their frequency / severity is neither increasing nor reducing.*
1F	Behavioural presentation has minimal impact on health status.	*The person presents occasional hazardous behaviours or has some rigidity of behaviour however these have been assessed and a package of proactive and reactive strategies agreed. These are consistently implemented and the outcomes of these strategies are closely monitored and regularly reviewed. The person has unimpaired access to an appropriate range of local health provision.*
0F	No presentation of risky behaviours / routines.	*The person does not present culturally abnormal behaviours which place themselves or others safety / wellbeing in jeopardy or risk the person being denied access to ordinary community facilities.*

5. Deficiencies in service quality and access Indicators.

A. Organisational barriers

There are a wide range of organisational barriers to accessing healthcare and other services. Some services are scarce or there may be eligibility criteria which prevent access. It may be difficult for people to physically access services e.g. they may be in a location that is far away or transport may be a problem. Services may not understand / or recognise the need to make 'Reasonable Adjustments'. Health care staffs often lack knowledge, skills and confidence, and on occasion, have negative attitudes in relation to people who have learning disabilities. This can lead to 'diagnostic overshadowing'.

Impact Level & Indicator Statement		Descriptor
4A	Organisational barriers causing major restrictions completely preventing access to services. No reasonable adjustments are in place.	*There are major difficulties in accessing services resulting from an organisation and/or its staff showing a complete lack of understanding and awareness about the nature of learning disabilities, there is a complete lack of recognition of diagnostic overshadowing and no evidence of reasonable adjustments being made. The attitude of staff towards the person may be unacceptable and discriminatory. Services are refused or inaccessible. Treatment or intervention is withheld, delayed or inappropriate. There is no support to access or even register with services. There may be serious safeguarding concerns in relation to organisational barriers to services.*
3A	Organisational barriers causing significant restrictions in access to services. Limited evidence of reasonable adjustments being made.	*There are significant difficulties resulting from an organisation's limited understanding and awareness about the nature of learning disabilities. There is poor recognition of diagnostic overshadowing and limited evidence of reasonable adjustments being made. Service provision is inadequate or difficult to access. There is very little support to access services. Frequent unreasonable delays in treatment or intervention. There is no training available.*
2A	Organisational barriers causing consistent restrictions in access to services. Reasonable adjustments are limited and inconsistent.	*There are consistent difficulties in accessing services which arise as a result organisational constraints and barriers. The understanding and awareness of those providing support about the nature of learning disabilities, the recognition of diagnostic overshadowing and the implementation of reasonable adjustments is limited and inconsistent. Limited awareness training or support is in place, occasional unreasonable treatment delays. There is limited support to access services.*
1A	Organisational barriers causing occasional restrictions in access to services. Reasonable adjustments are in place but may have some limitations.	*There are occasional difficulties in accessing services that are due to organisational barriers / inflexibility of care pathways. Organisations and their staff show a reasonable understanding and awareness of the nature of learning disabilities, its impact on health and the impact of diagnostic overshadowing. Reasonable adjustments are made though may be limited in range, scope and individualisation. Awareness training is in place for staff, although is not mandatory and some key staff have not been trained leading to some inadequacy and inconsistency in service provision. There is some support to access services.*
0A	No organisational barriers causing restrictions in access to, services. Full reasonable adjustments are in place.	*There are no difficulties associated with organisational barriers in accessing services. Services and their staff show a good understanding and awareness about the nature of learning disabilities, its impact on health, the need to avoid diagnostic overshadowing and the importance of reasonable adjustments to ensure timely access to assessment, investigations, diagnosis and treatment. Mandatory learning disability awareness training is in place for all staff. There is adequate support to access services.*

B. Consent

People with learning disabilities may or may not have capacity to give consent; or their capacity may vary from time to time and from issue to issue. Sometimes professionals do not take the time to gain consent from the person with the learning disability, even if they may have capacity. Understanding of the mental capacity act or other appropriate national legislation can be limited and appropriate best interests processes are not always followed when making decisions for those who lack capacity. Training is not always available or accessed.

Impact Level & Indicator Statement		Descriptor
4B	Consent or best interest process not in place or not being implemented.	*This level applies where there are major difficulties resulting from major procedural breaches in gaining consent, assessing capacity where required, or in following appropriate best interest procedures. Or, the person's care and treatment amounts to a deprivation of liberty which has not been lawfully authorised. No training is in place. There may be serious safeguarding concerns in relation to consent.*
3B	Consent or best interest processes in place but being ignored or wrongly applied.	*There are significant difficulties resulting from treatments or practices being carried out without lawful consent; or from procedural lapses which lead to delays, inappropriate withholding of treatment, or the person's rights not being upheld. Or no training in place.*
2B	Consent and best interest processes in place and being applied but with consistent lapses of rigour.	*There are consistent minor difficulties resulting from inconsistent approaches and procedural lapses in assessing capacity and gaining consent; or in following appropriate best interest processes; or in respecting the person's choices - these have not however placed the person at risk of harm. Restrictions of liberty may be in use following best interests' decision processes for a person who lacks capacity but these do not amount to a deprivation of liberty. Training is in place but is not mandatory.*
1B	Consent and best interest processes in place and generally being applied effectively, with occasional lapses.	*There are occasional minor difficulties or misunderstandings resulting from inconsistencies in involving the person in making their own decisions regarding their healthcare, in gaining their consent to any specific procedures that are to be undertaken and to properly assessing their capacity if this is questioned. If people are unable to consent to a treatment there may be minor lapses in terms of following appropriate best interests decision making processes. These lapses have not led to treatment being given without authority, has not incurred undue delays and has not placed the person at risk of harm. Mandatory training for staff is in place.*
0B	Consent and best interest processes are robust and rigorously applied.	*There are no difficulties related to consent issues. The person is supported to make their own choices where they are able, and these are respected. If it has been determined that the person lacks capacity to make a particular decision an appropriate and transparent best interest decision making process is followed (with full family and where appropriate advocacy involvement). If a person's care and treatment includes continuous supervision and control and they are not free to leave; and they don't have the capacity to agree to this then there is a clear lawful authorisation of this Deprivation of Liberty. Mandatory training around supporting decision making is in place, monitored and fully complied with.*

C. Transitions between services

Transition between services is often reported as problematic for some people with learning disability; this may for example include transition from children's services to adult or adult to older people's services, but equally could be transition between hospital services and home or community services, or transitions from one phase of education to another. Common problems include poor planning, variable and mismatched eligibility criteria, lack of clarity from professionals and poor co-ordination between services, together with low levels of satisfaction among family carers.

Impact Level & Indicator Statement		Descriptor
4c	Complete breakdown in transition arrangements between services.	*This level applies where there are major difficulties resulting from poor practices in transition processes. There will be no named coordinator to enable transition and policies protocols will be non-existent or completely inadequate. This may result in no appropriate service or completely unsafe services being provided and serious delays in the effective transition of services. There may be serious safeguarding concerns in relation to transition between services.*
3c	Regular and significant breakdown in transition between services.	*This level applies where there are significant difficulties resulting from poor practices in transition processes. There will be very little coordination available to support transition; policies and protocols are flawed, ineffective and require updating. Communication is poor and difficulties with information sharing seriously undermine effective support planning. This results in unsafe or unsatisfactory services being provided and significant delays in the effective transition of services.*
2c	There are consistent difficulties with transition between services.	*There are consistent minor difficulties resulting from poor practices in transition planning. There may be a named coordinator available to support transition but the role may not be effective; policies and protocols may require updating. This may result in unsafe or inadequate services being provided and significant delays in effective transitions between services.*
1c	Transition between services is successful, given appropriate additional support.	*There are occasional minor difficulties with transition processes. There will be a named coordinator available to support transitions; and relevant policies and protocols are current. Minor difficulties may relate to information sharing, communication, administrative arrangements or support for the person. These difficulties are likely to give rise to occasional delays in effective transitions between services requiring additional support.*
0c	Transition between services is successful and well-coordinated, with no additional support required.	*This level applies where there are no identified difficulties related to transitions between services. There will be a named person to coordinate arrangements and support the transition. Their role is embedded within local policies/ protocols. Local services are well placed to ensure smooth and effective transition pathways. No additional support is required.*

D. Health screening / promotion

Access to health promotion may be significantly poorer for people with more severe learning disabilities and people with learning disabilities who do not use learning disability services. In particular people are less likely to access assessment for vision or hearing impairments; routine dental care; cervical smear tests undertake breast self- examinations or attend for mammography.

Sometimes care staff are not sufficiently trained and have limited skills to effectively engage people with learning disabilities in health promotion activities and many don't know important relevant information such as a person's family history.

Impact Level & Indicator Statement		Descriptor
4D	Major restrictions in the quality of, or access to, health promotion / screening.	*This level applies where health screening / promotion programmes and activities are not available to meet identified needs. This may be because there is a lack of service provision or support or that access is being denied or withheld. Those providing support have no training and skills to promote and support good health. There may be serious safeguarding concerns in relation to health screening or health promotion.*
3D	Significant restrictions in the quality of, or access to, health promotion / screening.	*This level applies where some health screening / promotion programmes and activities are available but access or support may be restricted, delayed or not available. It is likely that no reasonable adjustments are in place. Those providing support have very little training or skills to promote and support good health. There may be areas of identified need that are not being met.*
2D	Some limitations in the quality of or access to health promotion / screening.	*This level applies where health screening / promotion programmes and activities are being provided but there are limitations in the scope of the service or support available and the degree or effectiveness of reasonable adjustments Those providing support have limited training and skills to promote and support good health.*
1D	Minimal restrictions in the quality of, or access to, health promotion / screening.	*This level applies where health screening / promotion programmes and activities are available to meet identified needs and are being accessed with minimal restrictions. There are some accessible materials, Those providing support have some training and skills to promote and support good health. Reasonable adjustments are negotiated and implemented.*
0D	No identified restrictions in the quality of, or access to, health screening / promotion.	*This level applies where there is full access and support to health screening / promotion programmes and activities. There are accessible materials, and person centred reasonable adjustments. Those providing support are adequately trained and skilled to promote and support good health.*

E. Primary / secondary care

People who have learning disabilities may access primary and secondary health care less frequently than the general population for screening, assessment, treatment and other interventions. Annual health checks including health screening should be conducted by primary care; and follow up and treatment provided appropriately to ensure health needs are met in a timely manner. All health services should be ensuring reasonable adjustments are made to enable access to the same health outcomes as would be expected for people who do not have learning disabilities.

Impact Level & Indicator Statement		Descriptor
4E	Major restrictions in the quality of primary / secondary care.	*This level applies where primary and secondary care services are not available to meet a range of identified needs. This may be because there is a lack of service provision locally or that support to use the service is being denied, or withheld. There may be serious safeguarding concerns in relation to primary or secondary health care services.*
3E	Significant restrictions in the quality of primary / secondary care.	*This level applies where some primary and secondary care services are available to meet identified needs but support to use services may be restricted, are delayed, or not available locally. It is likely that very few relevant and individualised person centred approaches in place. There may be areas of identified need that are not being met. There may be poor communication and differences of opinion between primary and secondary care providers.*
2E	Some restrictions in the quality of primary / secondary care.	*There are some limitations to the range of primary and secondary care services that are available locally to meet identified needs. Where such services are being provided, there are limitations in the scope of the service, the support available and the degree or effectiveness of person centred approaches. Or a limited service is available but the individual has good support and access is good.*
1E	Minimal restrictions in the quality of primary / secondary care.	*This level applies where full high quality primary and secondary care services are available locally and are being accessed with appropriate support, despite some occasional and minimal restrictions. Person centred approaches are negotiated and implemented. There is good liaison between primary and secondary care and an appropriate level of support to the individual.*
0E	No identified restrictions in the quality of primary / secondary care.	*This level applies where full high quality primary and secondary care services are available locally and are being accessed with appropriate support, despite some occasional and minimal restrictions. Person centred approaches are negotiated and implemented. There is good liaison between primary and secondary care and an appropriate level of support to the individual.*

F. Non health Services

Wellbeing, health and quality of life are influenced by services other than health services including for example social care, education, employment, housing, transport and leisure services; this may be especially true for people with learning disabilities who may be regular users of these services.

All public services should be ensuring reasonable adjustments are made to enable access and equal outcomes as would be expected for people who do not have learning disabilities.

Impact Level & Indicator Statement		Descriptor
4E	Major restrictions in the quality of person centred non-health services.	*This level applies where no non-health services (e.g. community social groups, leisure facilities, libraries etc.) are available to meet identified needs that cannot otherwise be met. This may be because there is a lack of service provision locally or that access or support is being denied or withheld. No effective person centred approaches are in place. There may be safeguarding concerns in relation to non-health services.*
3E	Significant restrictions in the quality of person centred non-health services.	*This level applies where only a few local non-health services are available (e.g. community social groups, leisure facilities, libraries etc.) to meet identified needs; access or support may be restricted or delayed. It is likely that very few relevant and individualised person centred approaches in place. There may be areas of identified need that are not being met.*
2E	Some restrictions in the quality of person centred non-health services.	*This level applies where a limited range of non-health services are available locally (e.g. community social groups, leisure facilities, libraries etc.) the person accesses them to meet identified needs but there are limitations in the scope of the services or the support available and the degree or effectiveness of person centred approaches.*
1E	Minimal restrictions in the quality of person centred non-health services.	*A wide range of quality non-health services are available which can meet some areas of a person's identified needs (e.g. community social groups, leisure facilities, libraries etc.) and these are being accessed as required, with appropriate support and minimal restrictions. Person centred approaches are negotiated and implemented.*
0E	No identified restrictions in the quality of person centred non-health services.	*This level applies where there is a wide range of high quality non-health services available to meet identified needs (e.g. community social groups, leisure facilities, libraries etc.). These are being accessed, as required, without restrictions. Services are effective and person centred.*

eHEF+ user manual

Introduction

eHEF+ is the electronic interface which is used to record service users' exposure to the determinants of health inequalities and to create profiles. It is a Microsoft Excel-based tool that has been designed to be portable and run on most systems. eHEF+ runs on Excel versions 2003 and above and Excel for MAC.

System requirements

- Hardware: PC or MAC
- Software: Microsoft Excel 2003 or later
- Screen Resolution: 1280 pixels wide or higher

Data security

Corporate users of the eHEF+ are advised to ensure that they are aware of; and compliant with, their organisational information governance, data security, data protection and other relevant. In particular, users should be aware that it is not advisable to email eHEF+ to anyone without due consideration for the security of the data contained within it.

Storage/saving eHEF+

Single Users:

- If you are working alone then you should simply store eHEF+ in a convenient location on your computer.
- The default file name is just eHEF.xls. You are free to change this if you wish but it is recommended you keep the first part of the filename intact. E.g. you may choose to name yours: eHEF – Jane.xls (if you are called Jane)

Multi User Setup:

- Because eHEF+ has been developed on a Microsoft Excel Spreadsheet it can only be opened and worked on by a single user at any given time. Providers are advised to configure files so that users can

still have ready access to the eHEF+. The simplest work around for this difficulty is to configure eHEF+ spreadsheets either for individual staff members or for small teams.

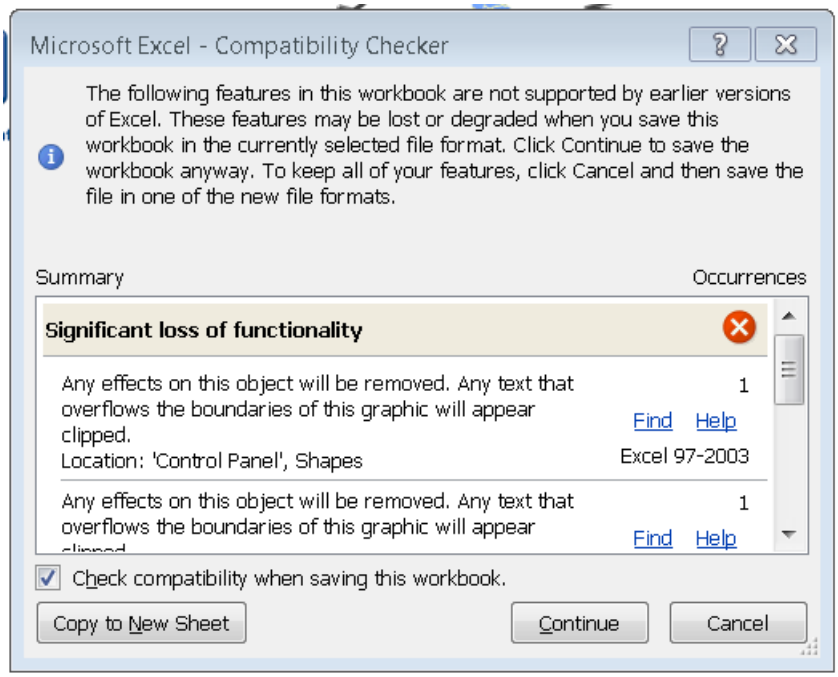
- If you work within a team where others are also using copies of the eHEF+ then it is recommended you store all the team's eHEF+'s in the same shared network folder.
- This will facilitate data aggregation which is managed by eHEF Manager, a separate tool. eHEF Manager has its own user manual.
- For multi user setup, it is essential that file names are unique and that you can easily identify your eHEF within the shared folder. A suggested convention might be the use of your first and last initials with the date of your birthday. Example, if your name is Simon Hughes and your birthday is on 5th September, you would call your file eHEF – SH0509.xls.
- It is essential that you keep the first part of the file name intact for eHEF Manager to be able to identify it and capture data from it for analysis. I.e. file names must begin eHEF+.

Note:

Users of the eHEF+ should remember to SAVE eHEF+ after adding or editing any data. Depending on the Excel version/settings it may AutoSave. Users are advised to check this or just SAVE in any case in order to be sure.

Compatibility Warning:

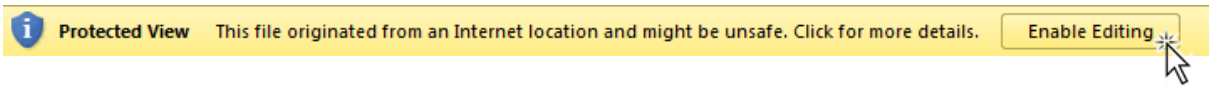
Because eHEF+ is designed to run on most versions of Excel you will sometimes (depending on your version) get a compatibility warning when saving. You can simply click 'Continue' and you may wish to clear the 'Check Compatibility' box for this file so you shouldn't be bothered by the warning again. None of eHEF+'s features will be compromised by keeping the file in its original format/version.



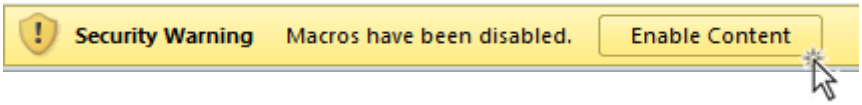
Opening eHEF+:

Once you have received your copy of eHEF+ and stored it with an appropriate name you will want to go ahead and start using it!

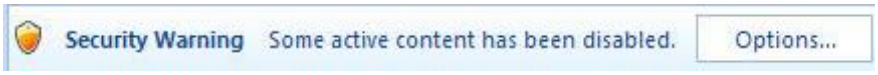
- Open eHEF+ as you'd open any other file (usually a double-click). You *may* receive a message prompting you to 'Enable Editing' to which you should agree.



- Next you'll need to 'Enable Macros'. The prompt for this action looks different according to your version of Excel and your security settings. Here is the Excel 2010 version of the prompt.



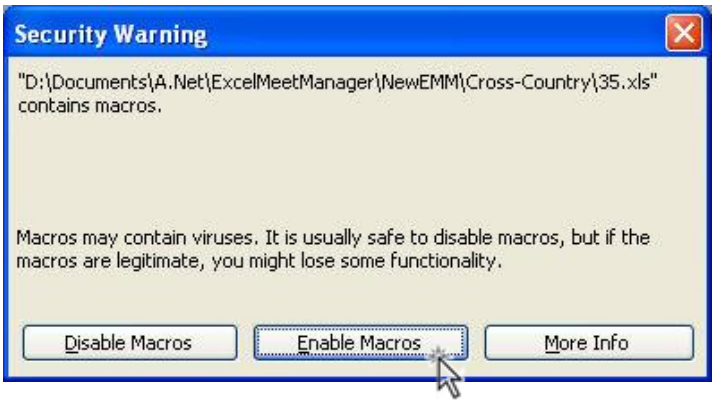
- If you have a copy of Excel 2007, you will see this message and you will need to click 'Options…



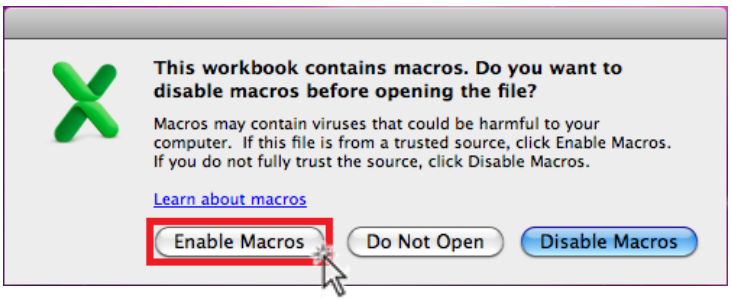
- Then 'Enable This Content' and then click OK.

- If you see this message instead, click 'Enable Macros'

- If you are using Excel 2003, you will see this prompt and need to click 'Enable Macros'.

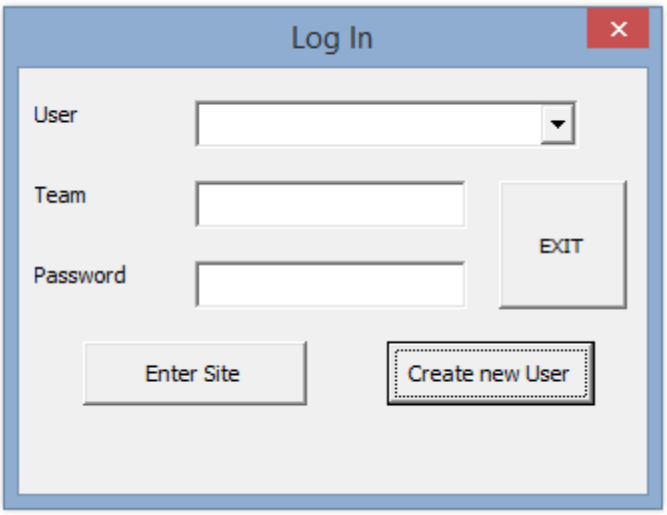


- If you are using a mac version of Excel, you will see this prompt and simply click 'Enable Macros'.

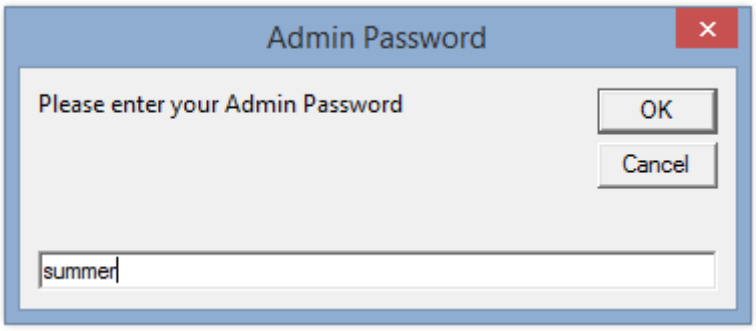


Creating a log-in:

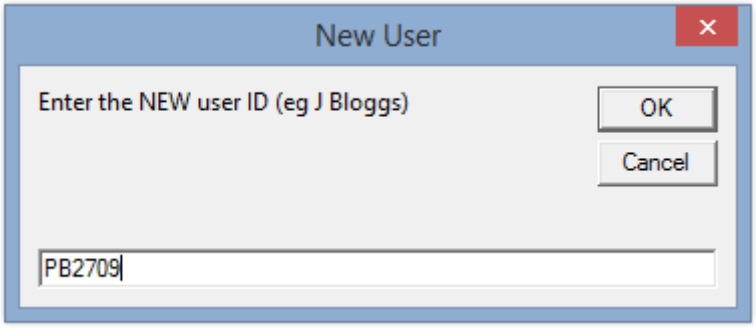
- If you are the system administrator you must create logins for people who will use the eHEF+.
- When the login screen pops up, click 'create new user':



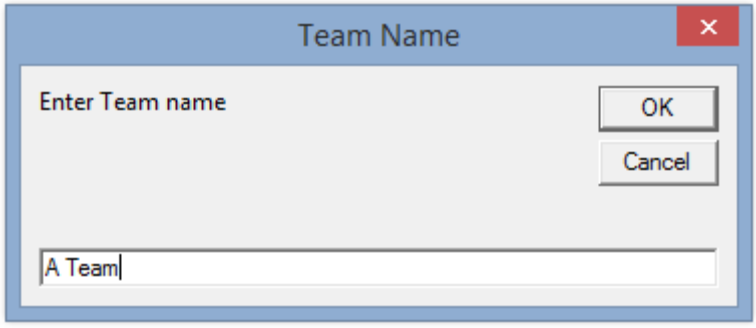
- You must then enter the administrator's password and click OK. By default the administrator's password is set to 'summer'.



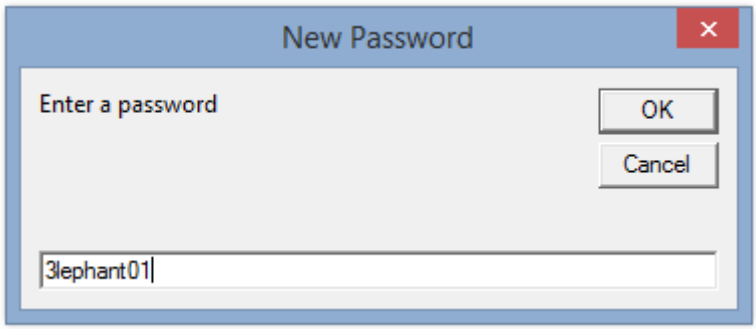
- Next, you create the new user's ID. It is recommended that you follow the convention (mentioned in the Storage section above) of using the person's first and last initials with the date of your birthday. For example, if your name is Peter Brown and your birthday is on 27th of September, your username would be PB2709.



- Then enter a team name. If you are a single user you can leave this blank. In a multi user environment the administrator should select a suitable (short) team name. This will be important for the eHEF Manager tool which has the ability to group data by team name.



- Finally the administrator should create a password for the user. This can be in any format.

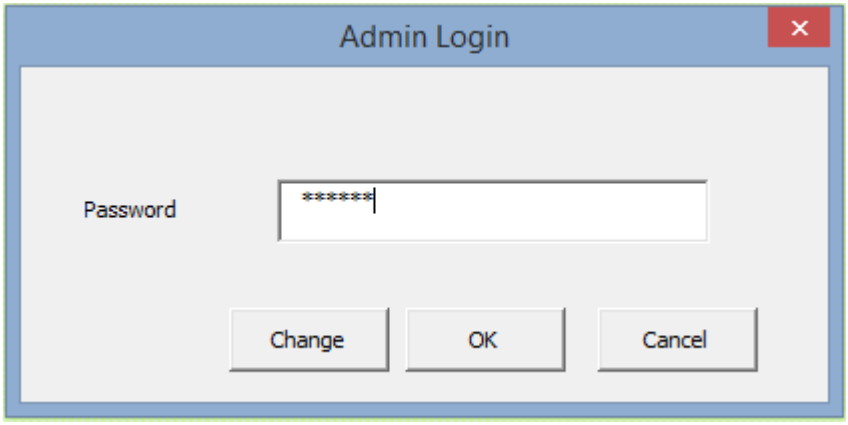


- Login details should then be shared with the user.

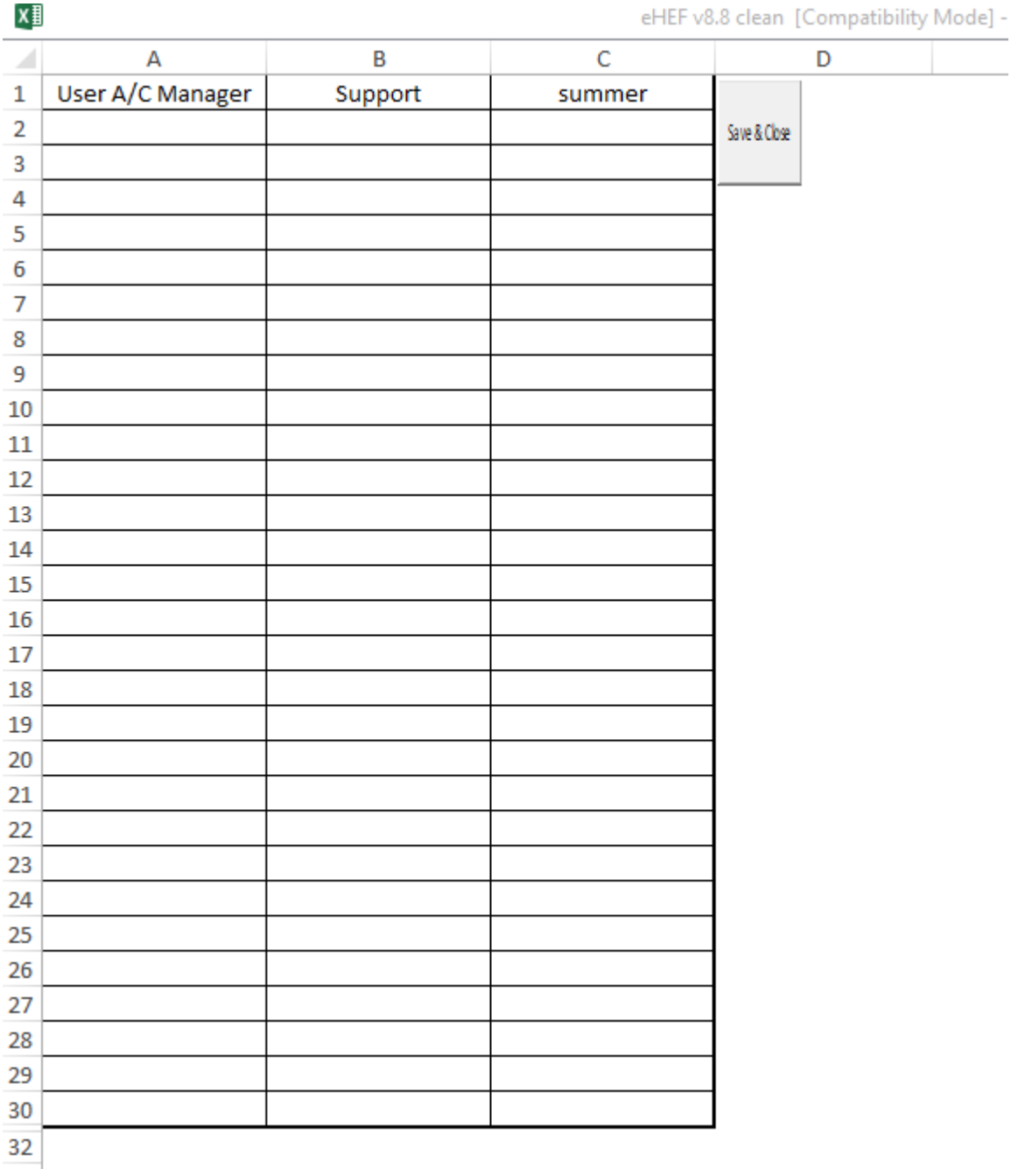
Changing the administrators password:

- The administrator's password is set to 'summer' by default. Given that this is reported in this manual it will need to be changed in order to ensure people's data is protected.
- Log in in the normal way. The administrator's username is set by default to ''User A/C Manager'. Use the default password 'summer' unless it has already been changed.
- From the front page click the eHEF+ User Admin button:

- You will be prompted once again to enter the current password:



- The master username, team name and password will open.

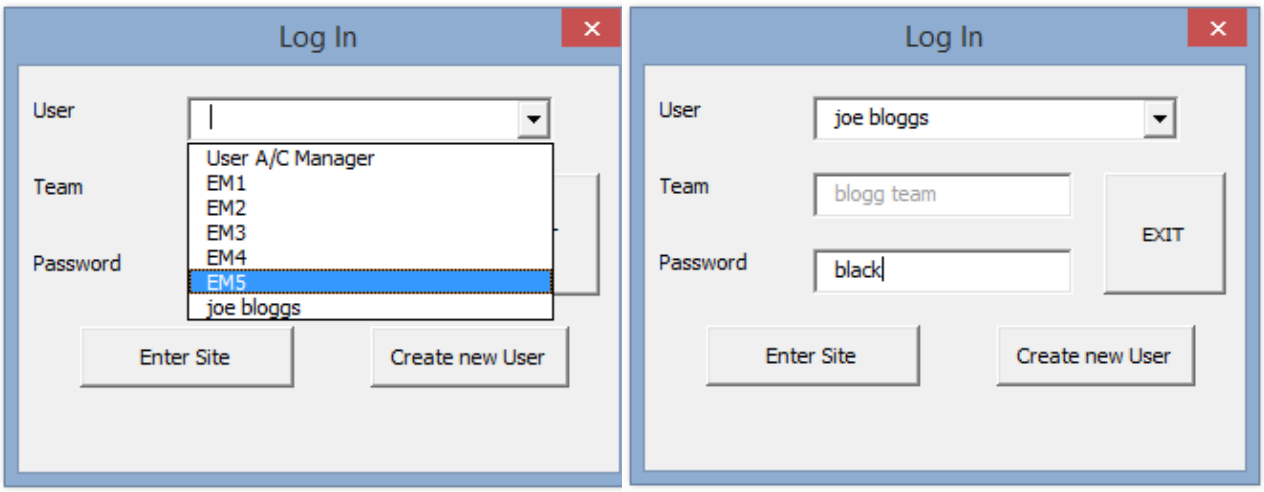


- Column A contains a list of user names. Column B lists team names. Column C lists password.

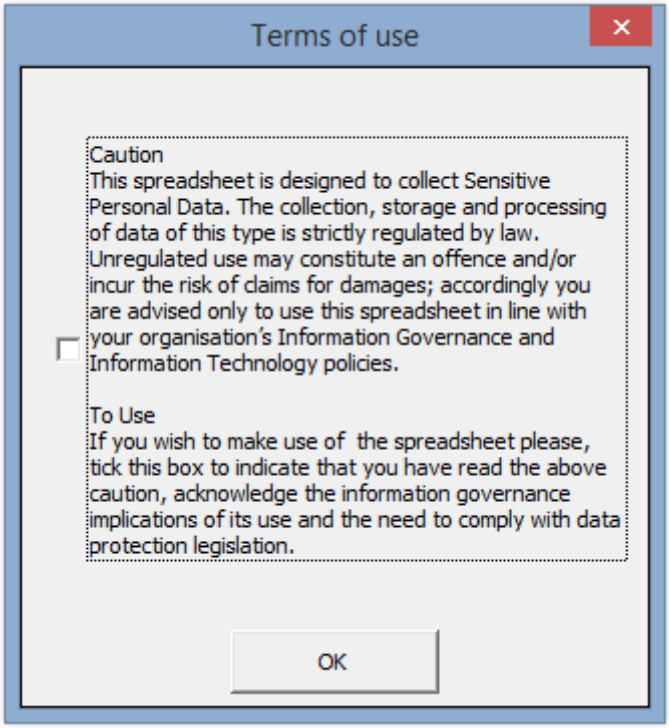
- On this sheet, passwords can be changed, users deleted, user names changed etc.
- Once all changes have been made click 'save and close' to return to the main eHEF+ interface.

Logging in to the eHEF+:

- To log into to eHEF+ users need a username and password. These can be created and issued by whoever is administrating the system.
- Once you have your username and password select your username from the dropdown menu. The team name will automatically be entered. Then type in your password and click 'enter site'.



- Each time you open the eHEF+ you will be required to agree with its Terms of Use by ticking the box and clicking 'ok' as shown below.

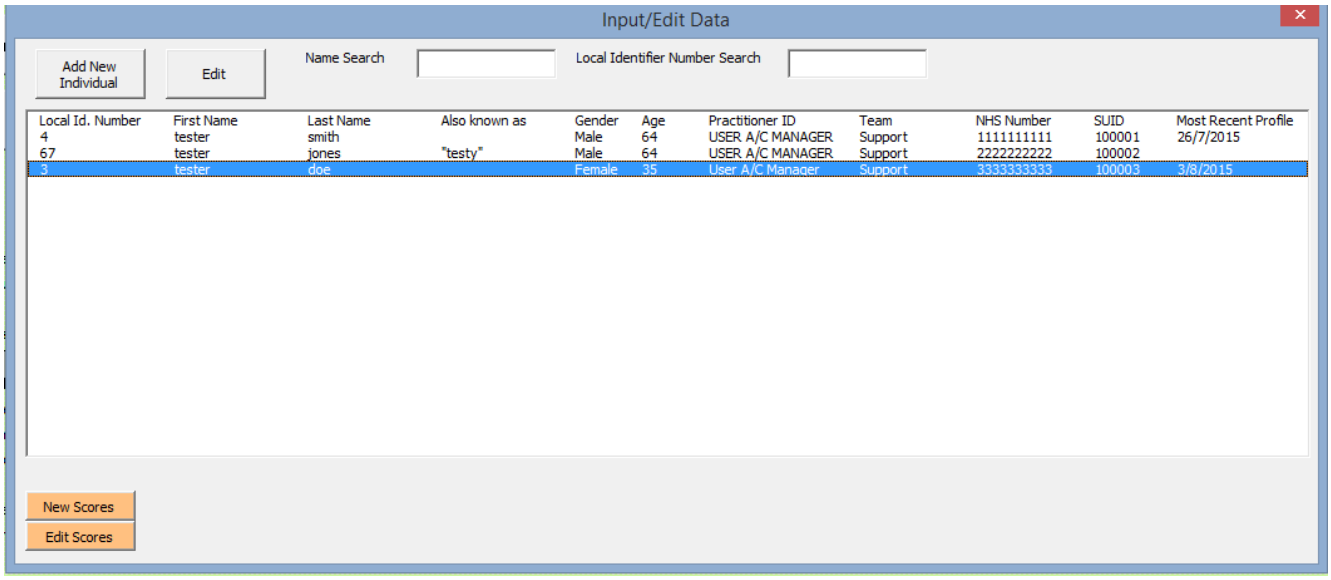


- The eHEF+ front page will then open:

- So from the eHEF+ front page users can navigate to:
  - Input / edit data - this is where service users can be registered on the system and ratings entered to indicate the impact of their exposure to the determinants of health inequality.
  - Report page - this allows HEF profiles to be generated, as well as comparisons over time to be made.
  - Log page - monitors and records who has used the eHEF+ and what activity they have engaged in.

Input / edit data

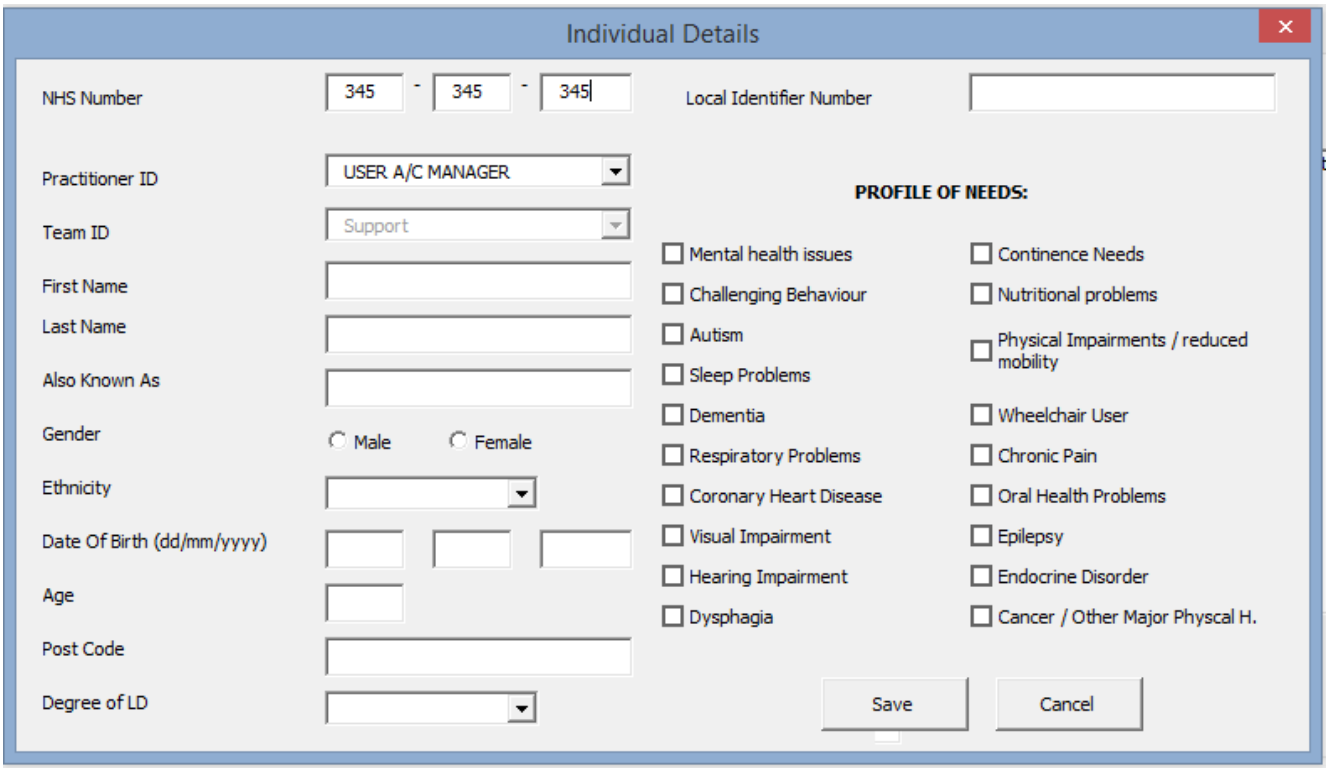
- After clicking on the Input/Edit Data button, the Input/Edit Data panel opens. This is used to add new individuals to the system, to edit their details, to enter scores (ratings) and to edit scores.



Adding a new individual:

To add a new individual to eHEF+ follow these steps.

1) Click 'Add New Individual'
2) Complete the individual's details
3) Click 'Save' and then confirm submission. You'll receive a prompt that the record has been saved



NHS Number should be entered in the top left hand box.

Local Identifier: The Local Identifier Number (not a mandatory field) is available to capture a reference number, or similar, that you might use within your organisation.

Practitioner and Team ID will automatically be entered.

Name, gender, ethnicity and date of birth should next be entered. Age will automatically be calculated.

The person's **post code** should be entered.

Next you should enter an indication of the **severity of the person's learning disability** (if known). This requires an informed judgement based on the person's presentation. It does not require a precise diagnostic assessment and does not replace more formal clinical records of diagnosis.

Finally, raters should then tick boxes to indicate the current profile of presenting areas of need. Again this does not require precise diagnoses (neither is the list of areas of needs exhaustive). A common sense approach is required to identifying areas of significant need which the rater feels the person presents.

Editing an individual's details:

1) From the Input/Edit Data panel first select the individual whose details you wish to edit
2) The click 'Edit' and off you go.
3) Make any necessary amendments / revisions.
4) Click 'Save' and confirm

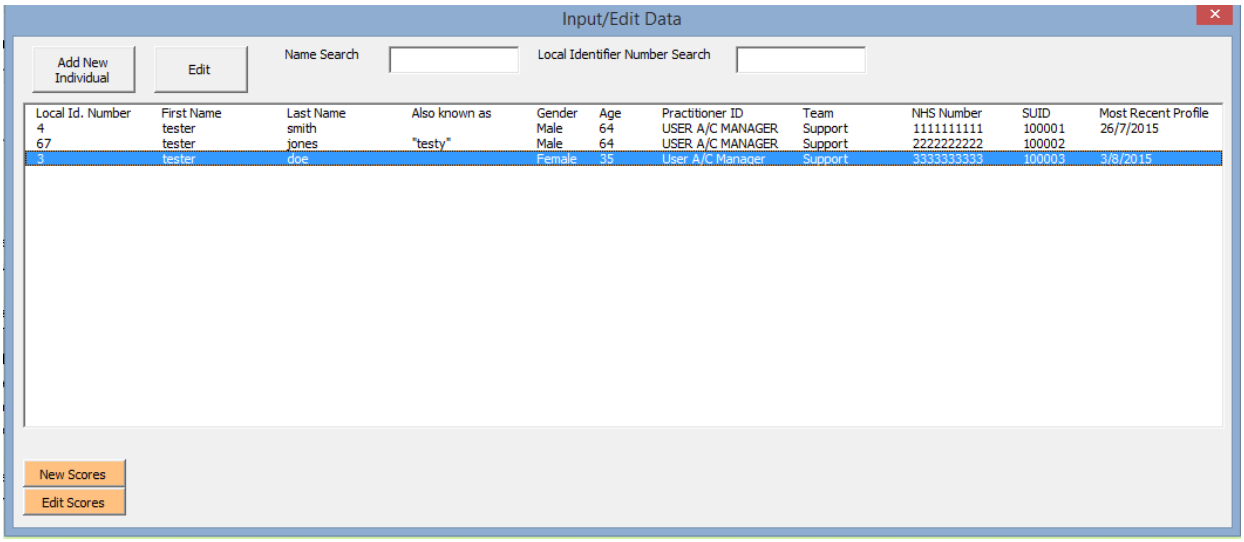
Note: you cannot edit an individual's name. This is to ensure consistency of data and prevent users from inadvertently over-writing a name.

Finding an individual:

There are three ways to find an individual:

1) You can simply scroll down your list until you find the person you're looking for. This will be fine if you only have a small number of individual's records.
2) Start typing the *first name* in the *Name Search* box. The nearest match will then be highlighted/selected

3) Use the Local Identifier Number Search box in the same way as above, simply start typing the reference/number in the search box and the nearest match will be highlighted



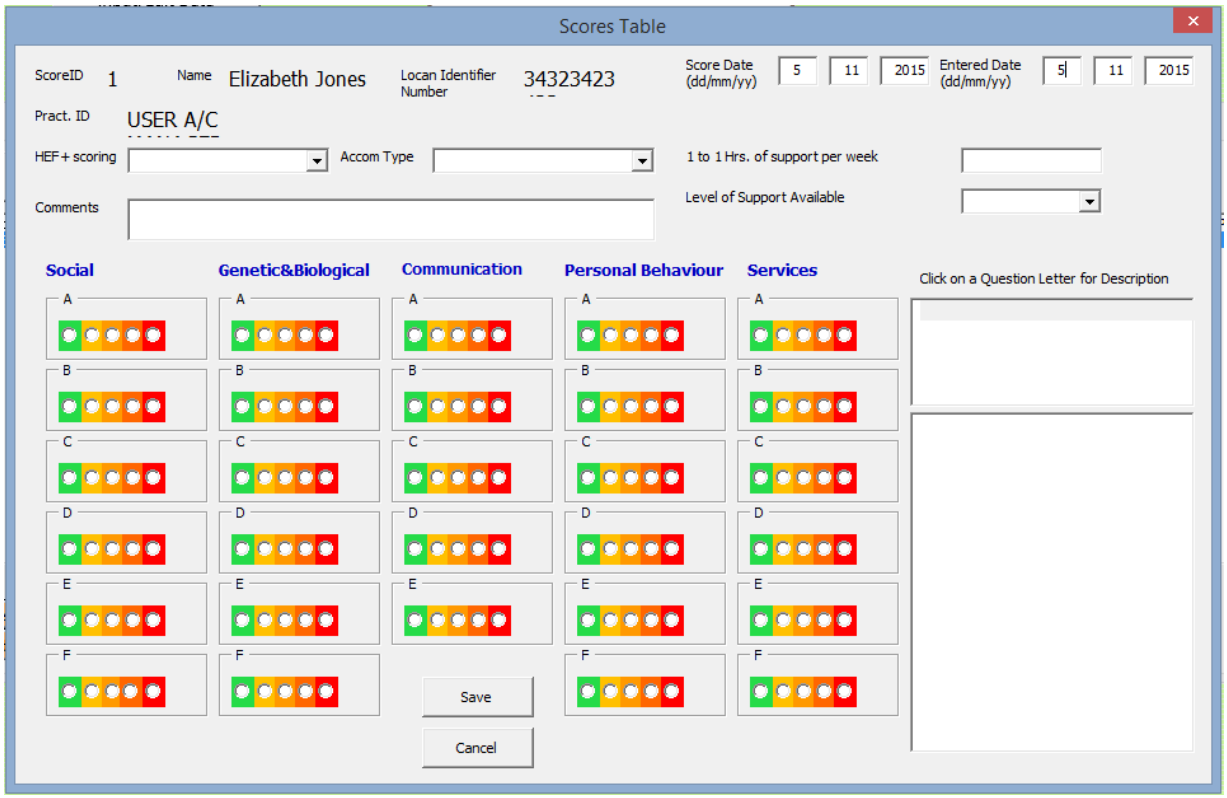
Profiling exposure to the determinants of health inequality:

Once you've added the details of one or more individuals to eHEF+ you can go ahead and start recording HEF assessment information.

1) Using one of the methods described in 'Finding an Individual', locate the person for whom you wish to capture a score set

2) Click 'New Scores'

3) The scores panel opens up ready for you to start entering ratings



4) Record the nature of the scores being entered i.e. whether this is a first profile, a follow up or a final set of ratings.

5) Then record the nature of the person's accommodation.

6) Raters should then record whether and if so how many, dedicated support hours are provided to the person.

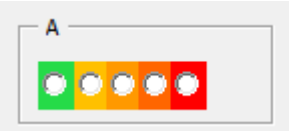
7) An indication as to whether the person's overall level of support has increased, reduced, or remained stable over recent times should be recorded next.

8) The comments box allows brief comments to be recorded which will assist in understanding the person's situation at the time of rating. This box does not replace the person's daily care records and therefore excessive detail is not required. It might for instance be helpful to note if the person has moved accommodation since the previous rating, or that they may have had a recent episode of acute ill health.

9) The person's exposure to the determinants of health inequality should then be profiled:

a. Until familiar with the HEF it can be useful to have a copy of the manual to hand.

b. Under each of the determinants are a series of 'radio' buttons which are used to record impact ratings for each indicator.



c. When you click on an impact rating, the corresponding indicator statement and descriptor appear in the boxes on the right hand side.

d. It is advisable for each indicator to work from red towards green in search of the first descriptor which encapsulates a service user's situation.

e. This process should be repeated for all 29 indicators.

10) Once you've completed all required fields click 'Save' and confirm

11) You will receive a prompt letting you know that the scores have been saved and the report page updated.

Required fields: Everything on this form is required to be completed except *Comments* and *1 to 1 Hrs. of support*. If you miss anything out eHEF+ will prompt you after you click save.

Editing a set of scores:

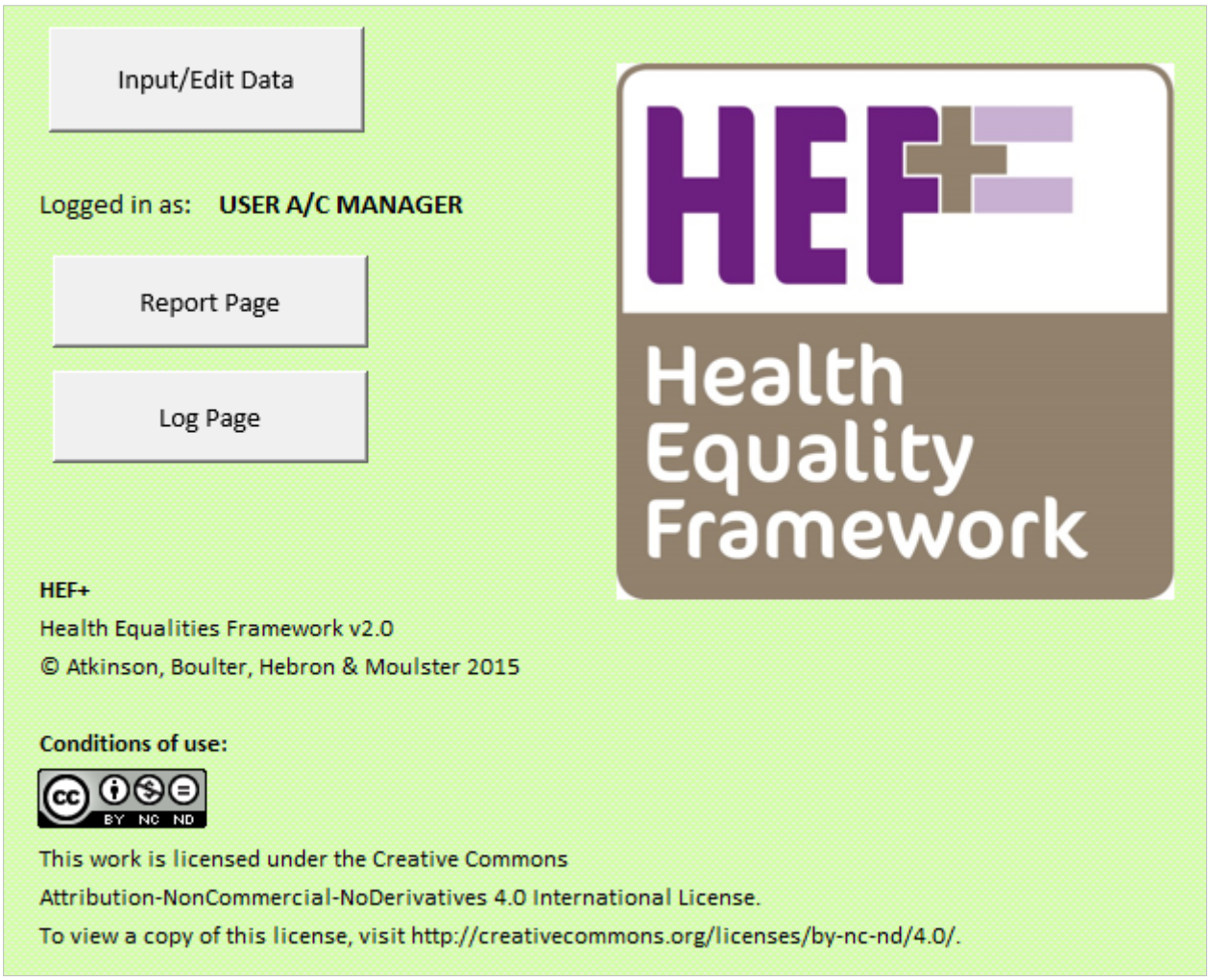
Whilst it is recommended you aim to record data accurately it is also recognised that you may occasionally have the need to make corrections or changes. So, the *Edit Scores* feature is available for this purpose. To use it:

1) Locate the individual whose scores you need to edit – see section above for a reminder of the options for searching
2) Click 'Edit Scores' – you'll then be prompted with the number of score sets for the individual
3) Click 'Ok' and in the next dialog box choose the score set you want to edit
4) The dates on which the scores were taken and logged are available to assist you find the right one
5) Select the score set you want to edit and click 'Edit'
6) Make your necessary changes and click 'Save'

Note: Remember you must complete the majority of fields in the scores form. If you leave any required fields blank eHEF+ will prompt you to complete them when you save.

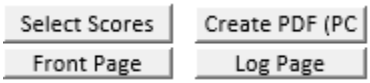
Creating reports:

To create a graphical summary of an individual's exposure to the determinants of health inequalities (HEF profile), navigate your way to the Front Page and then click on 'Report Page'. This will bring you to where you can create graphs to see one or two sets of data so you can see just one current or past set of scores or choose two to compare change over time.

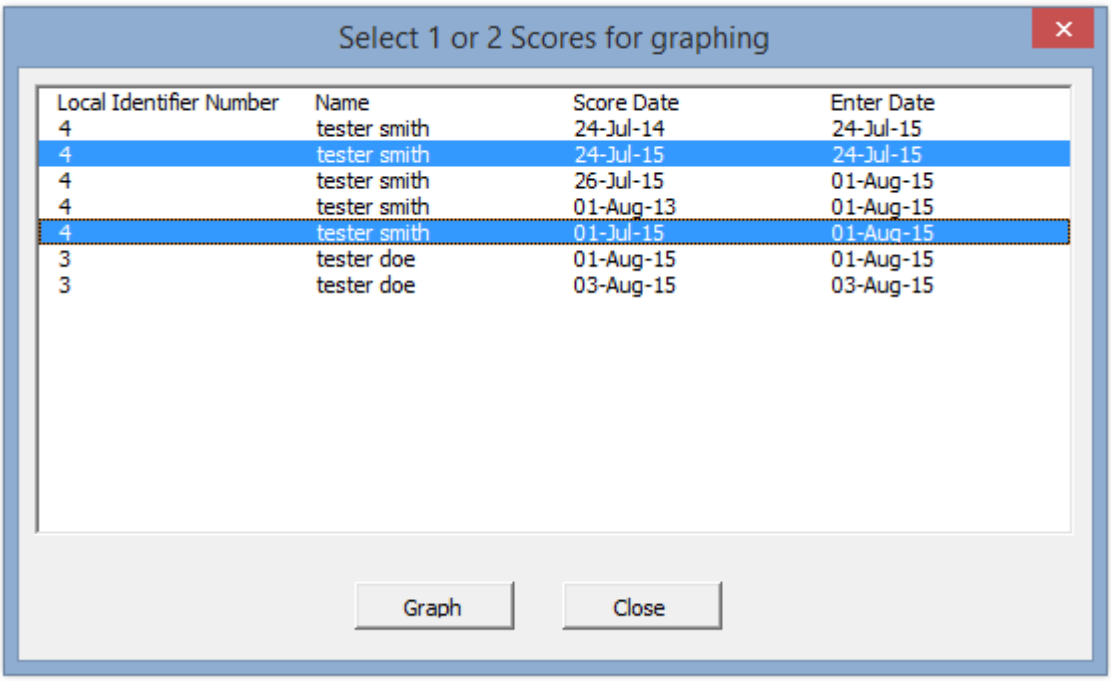


To create graphs, do the following:

1) Click on 'Select Scores for Graphs

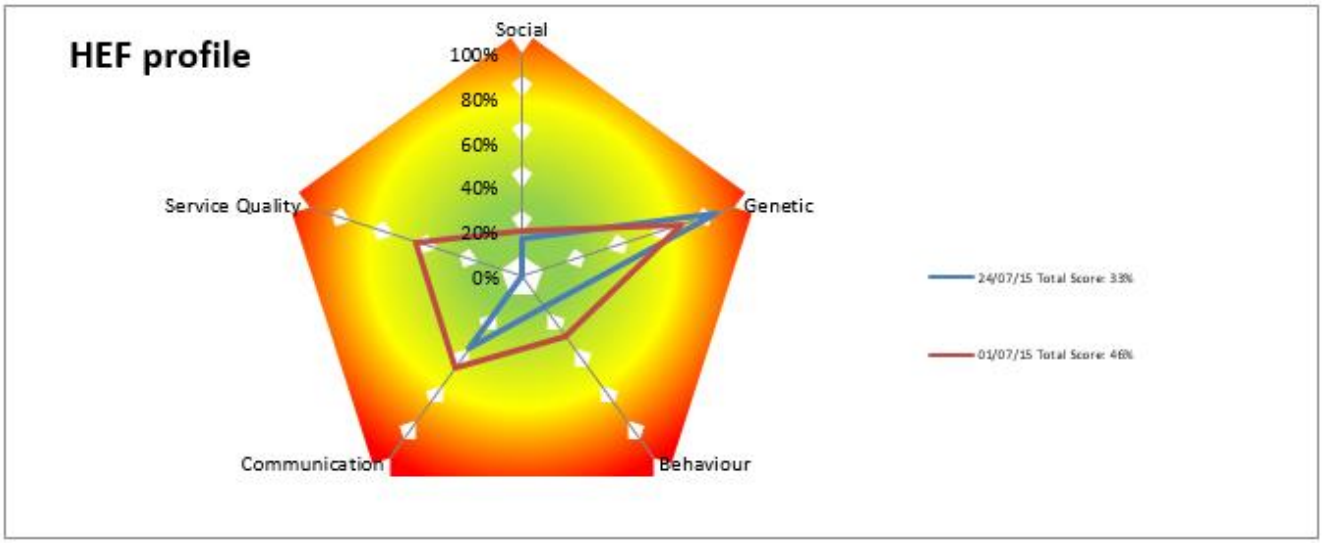


2) Select one or two sets of scores

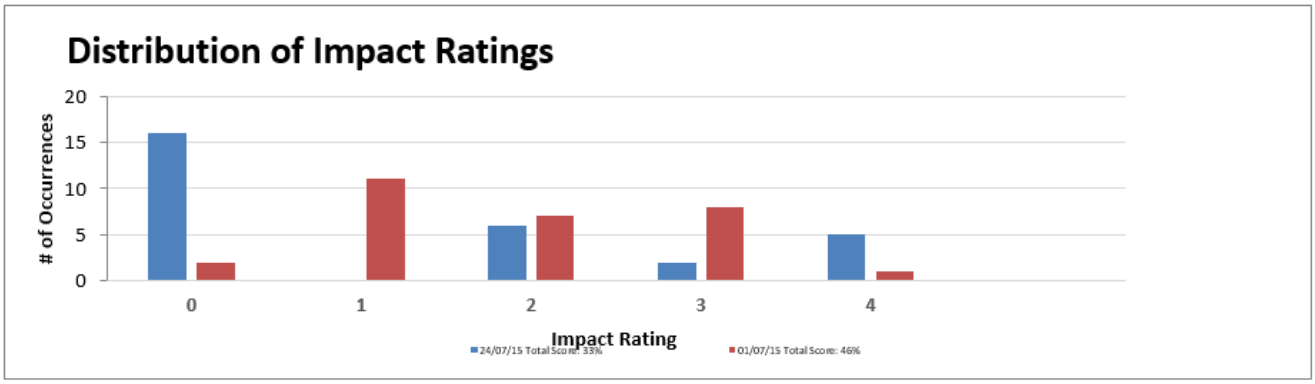


3) Click Graph and then graphs displaying scores for each of the sections will be created onto the current sheet. You may need to scroll down to see all of the graphs.

4) First of all you will see the HEF profile. This shows the proportionate exposure to each determinant on the basis of impact ratings for the underlying indicators. High levels of exposure suggest the greatest risk of an individual suffering serious health inequalities. This provides a high level summary which can be compared across time in order to measure the outcome of effective service delivery.

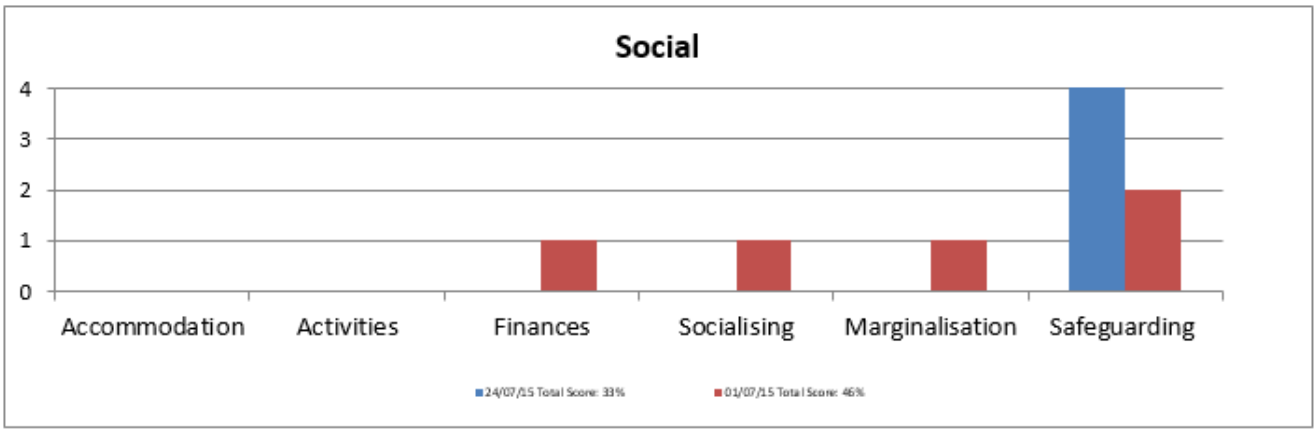


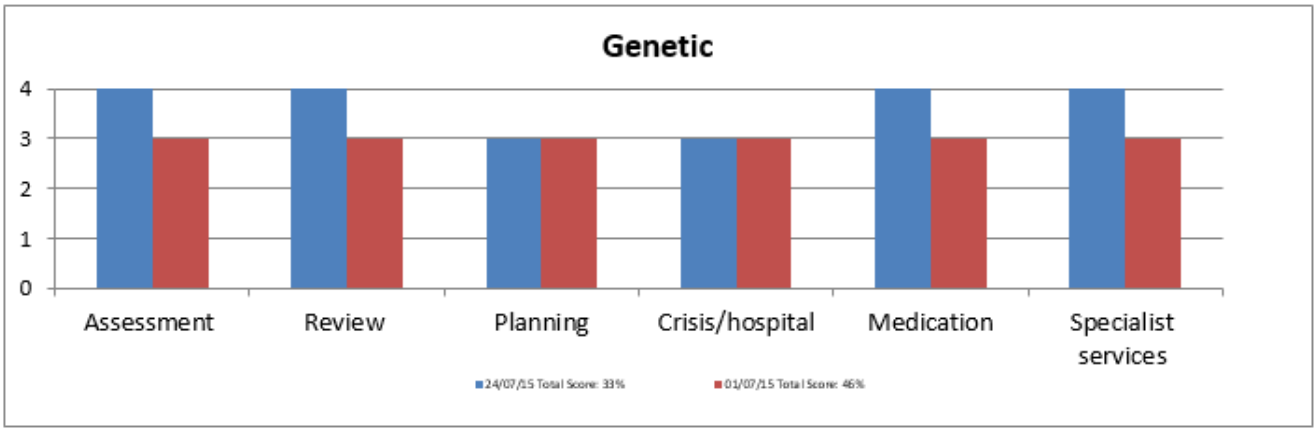
5) These high level ratings are only a summary and can mask high ratings against specific indicators which should be of significant concern. Consequently the next chart shows the 'distribution' of impact ratings. All high scores should be of particular concern and so it is helpful to quickly visualise the number of ratings of 3 and 4.

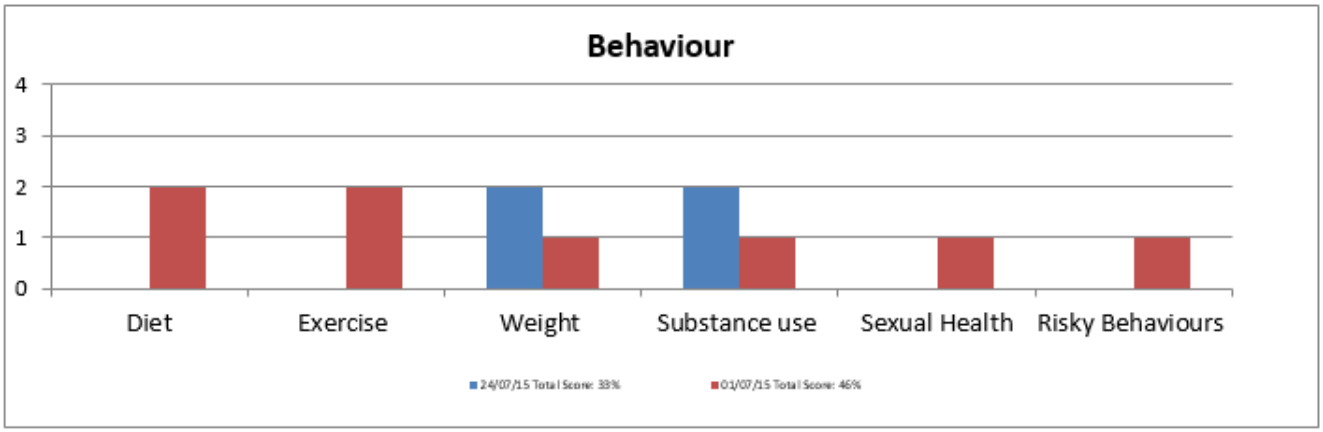


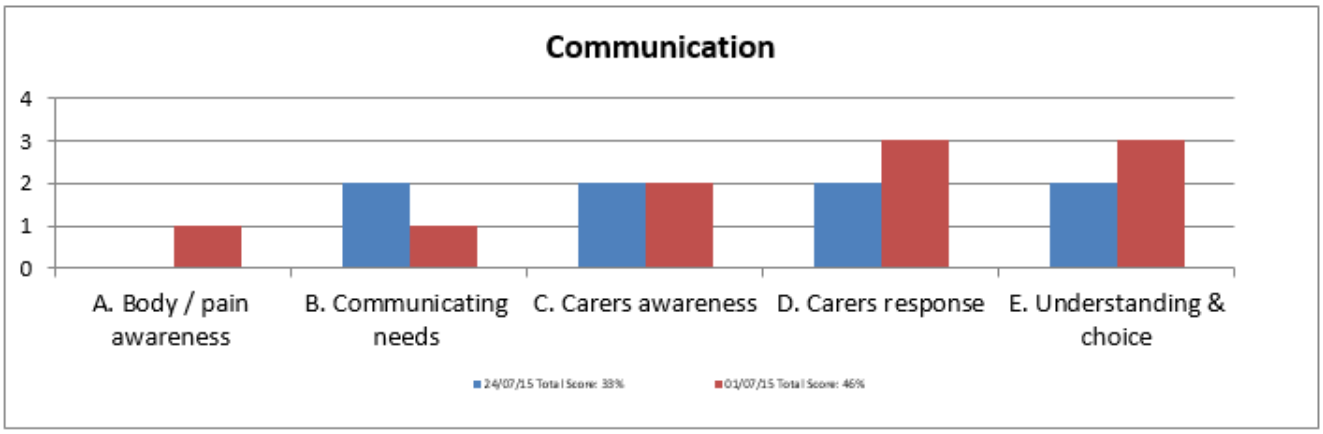
Where an impact rating for a particular indicator cannot be reduced (for some external reason), it is important to be transparent and acknowledge that this situation may contribute to serious health inequalities. It may also be that other indicators under the same determinant should be prioritised. So for instance, a person serving a prison sentence may need to be there for the purpose of public protection. It should however be acknowledged that this is potentially detrimental in terms of health outcomes and that close attention to other social indicators such as engagement in meaningful activity or maintaining important social networks may be even more important in terms of reducing the overall, combined impact of exposure social determinants.

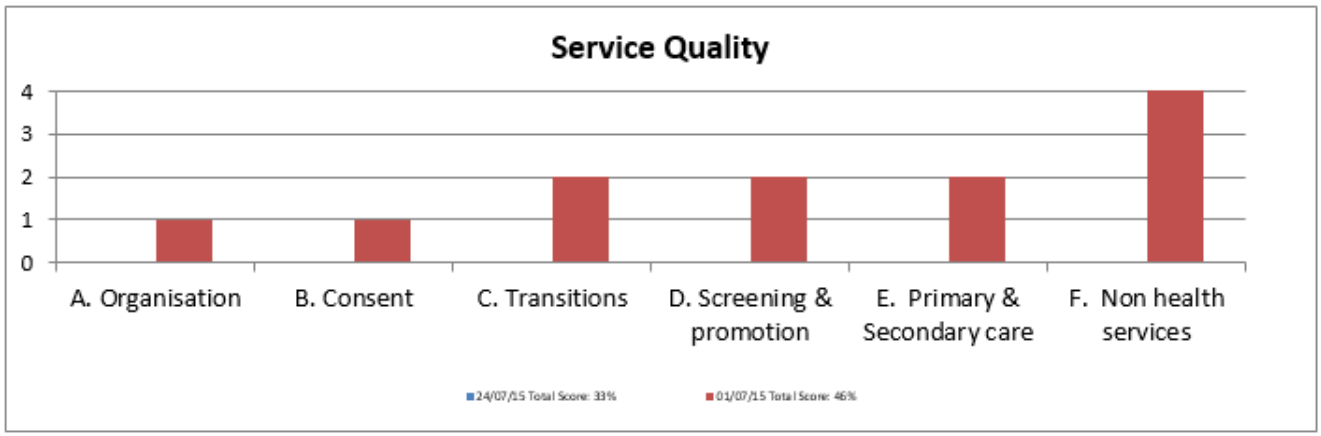
6) Users can then scroll down the page and see individual charts for each determinant. This allows the contribution of each indicator which underlies a determinant to be visualised. This can be particularly important when considering priorities to be targeted through effective care and support plans.







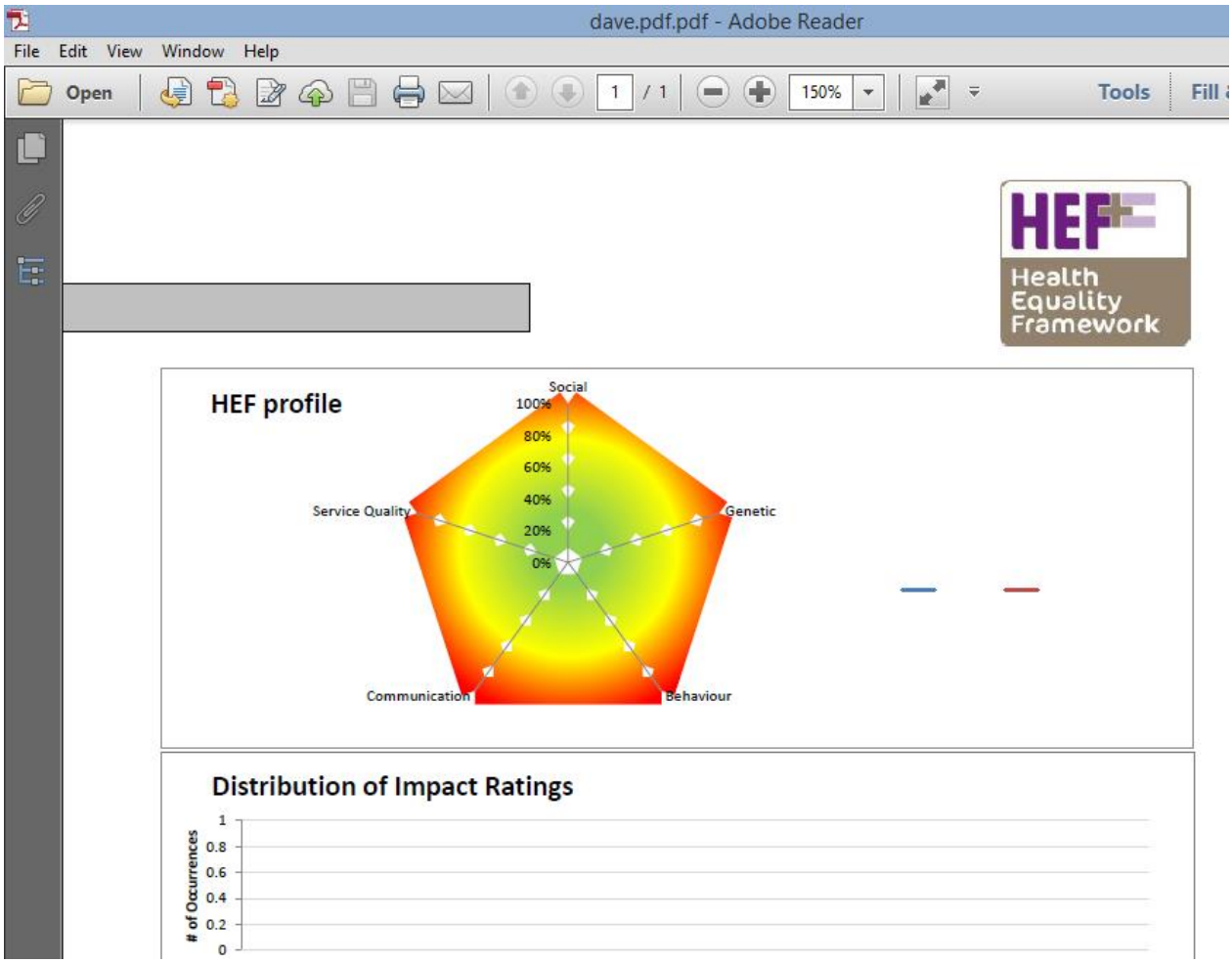




Creating a pdf Copy of the Profile

You can then create a PDF file displaying the profile and graphs you have just created by doing the following:

1) Click Create PDF (PC only) on the Report Page
2) Name the file appropriately
3) Find an appropriate place to save the PDF file
4) Click OK and then it will create the file and save it where you specified
5) Once saved, paper copies can be printed with ease.

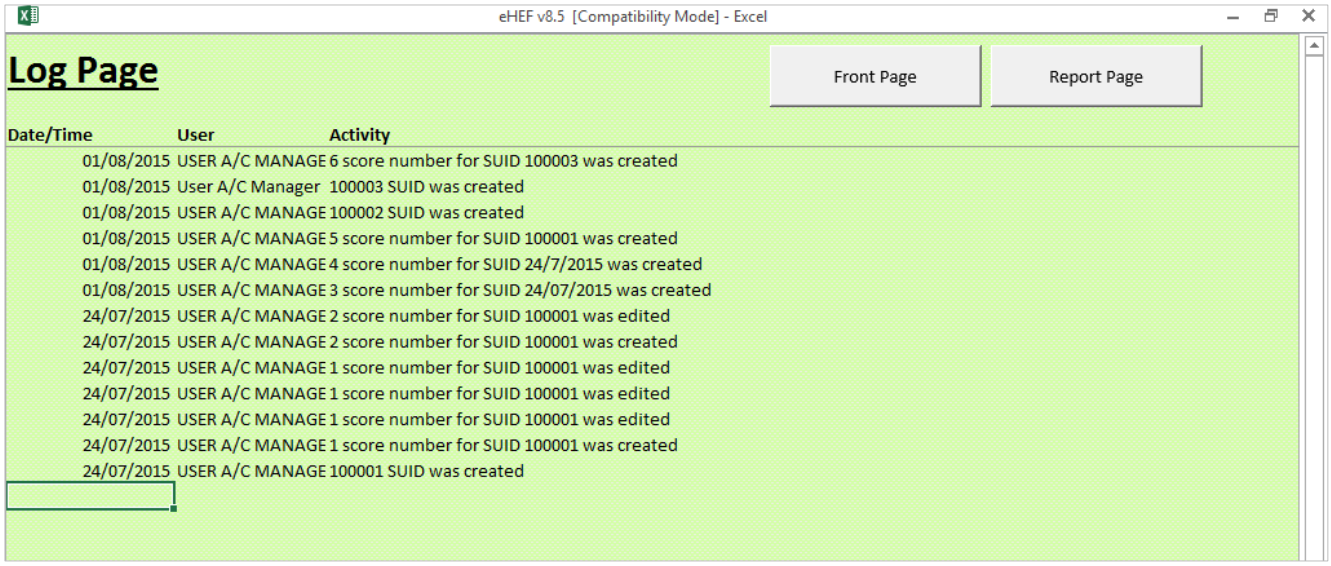


Activity logging:

For governance purposes, it is helpful to know who has been accessing the spreadsheet, when and for what purpose. Accordingly, the eHEF+ has a simple logging feature that keeps track of any significant activity. The following actions are logged:

1) New individual added
2) Individual's details edited
3) New HEF score added
4) HEF score edited

The log page is accessed via a button on the front page and opens a sheet which shows the following details:


eHEF v8.5 [Compatibility Mode] - Excel
Log Page
Front Page
Report Page
Date/Time User Activity
01/08/2015 USER A/C MANAGE 6 score number for SUID 100003 was created
01/08/2015 User A/C Manager 100003 SUID was created
01/08/2015 USER A/C MANAGE 100002 SUID was created
01/08/2015 USER A/C MANAGE 5 score number for SUID 100001 was created
01/08/2015 USER A/C MANAGE 4 score number for SUID 24/7/2015 was created
01/08/2015 USER A/C MANAGE 3 score number for SUID 24/07/2015 was created
24/07/2015 USER A/C MANAGE 2 score number for SUID 100001 was edited
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Appendix 1: Summary of indicators of health inequality

Indicators of the determinants of health inequality

Indicator statements associated with each impact level for the 5 determinants are presented below:

Determinant 1:	**Social determinants of poorer health such as poverty, poor housing, unemployment and social disconnectedness**	
Health Inequality Indicators		
A. Accommodation	**Impact**	**Rating**
Accommodation presenting high risk; imminent threat of loss of home; or in hospital / prison with no discharge accommodation identified; or homeless.	**Major**	**4**
Inappropriate accommodation / accommodation at risk of breakdown.	**Significant**	**3**
Accommodation shared with others / family – not by choice.	**Limited**	**2**
Settled single accommodation or shared with chosen others. No control over tenancy; care and accommodation by single provider.	**Minimal**	**1**
Settled family accommodation; or tenancy / ownership reflecting personal choice / best interests. Separate arrangements for accommodation and support.	**None**	**0**
B. Employment, activities and engagement	**Impact**	**Rating**
No meaningful activities / engagement.	**Major**	**4**
Highly restricted activity / engagement levels.	**Significant**	**3**
Limited meaningful activities / engagement.	**Limited**	**2**
Regular voluntary work or other structured meaningful activity / engagement.	**Minimal**	**1**
Fully engaged in activities suited to needs and preferences; typically including paid employment and/or education.	**None**	**0**
C. Financial support	**Impact**	**Rating**
Minimal or no financial support; or significant debts; or being financially abused.	**Major**	**4**
Highly restricted access to adequate financial support and / or significant restrictions on spending decisions.	**Significant**	**3**
Limited financial support with consequent restrictions on spending choices.	**Limited**	**2**
Full financial support / benefits accessed allowing a reasonable quality of life.	**Minimal**	**1**
Sufficient financial support to maintain good quality of life.	**None**	**0**
D. Social Contact	**Impact**	**Rating**
Minimal or no appropriate social contact. Largely socially excluded / isolated.	**Major**	**4**
Fragile social networks.	**Significant**	**3**
Social contact reliant on paid support or restricted.	**Limited**	**2**
Access to some non-paid social networks.	**Minimal**	**1**
Engages with a wide range of established, non-paid social networks.	**None**	**0**
E. Additional marginalising factors	**Impact**	**Rating**
Marginalising factor(s) having major impact on, or leading to, a highly restricting lifestyle.	**Major**	**4**
Additional marginalising factors present leading to isolation and having significant impact.	**Significant**	**3**
Some additional marginalising factors but impact on quality of life is minimal.	**Limited**	**2**
Minimal additional marginalising factors with no discernible impact; appropriate support is in place and effective.	**Minimal**	**1**
No additional marginalising factors over and above learning disability.	**None**	**0**
F. Safeguarding	**Impact**	**Rating**
Major concerns that abuse may be taking place.	**Major**	**4**
Significant concerns that the person is at risk of actual abuse.	**Significant**	**3**
Some concerns that the person is at risk of abuse.	**Limited**	**2**
Minimal safeguarding risks, though vulnerable.	**Minimal**	**1**
No safeguarding concerns.	**None**	**0**

Determinant 2:	Physical and mental health problems associated with specific genetic and biological conditions in learning disabilities	
Health Inequality Indicators		
A. Assessment of physical and mental health needs; and health checks	**Impact**	**Rating**
Physical and/or mental health not assessed. Little or no understanding of needs.	**Major**	**4**
Assessment has commenced. Only superficial needs recognised. Ongoing delays due to multiple obstacles.	**Significant**	**3**
Superficial assessment completed but delays accessing treatment or further assessment.	**Limited**	**2**
Assessment completed but not fully informed. Needs have been described.	**Minimal**	**1**
Physical and/or mental health needs comprehensively assessed and fully understood.	**None**	**0**
B. Planned reviews of need	**Impact**	**Rating**
No effective ongoing review mechanisms.	**Major**	**4**
Inadequate arrangements for reviews.	**Significant**	**3**
Care plans reviewed but not inclusive of all relevant parties.	**Limited**	**2**
Regular, effective, appropriate and responsive reviews undertaken.	**Minimal**	**1**
No significant health needs, review not required.	**None**	**0**
C. Care Planning / Health Action Planning	**Impact**	**Rating**
No Care plans / Health Action Plans in place.	**Major**	**4**
Non condition specific care plans / Health Action Plans in place (not in accordance with evidence base e.g. NICE guidance).	**Significant**	**3**
Condition specific, generic care plans / Health Action Plans in place. Plans may be incomplete.	**Limited**	**2**
Condition specific person centred care plans and Health Action Plans in place.	**Minimal**	**1**
No care plans or Health Action Plans required.	**None**	**0**
D. Crisis / emergency planning and hospital passports	**Impact**	**Rating**
Despite clear evidence of need, no crisis, emergency or relapse plans; or hospital passport (where appropriate) in place.	**Major**	**4**
Crisis / emergency / relapse plans and hospital passport inadequate, not person centred or reviewed; or consistently not utilised.	**Significant**	**3**
Crisis / emergency /relapse plans and hospital passport as appropriate in place, not reviewed or occasionally not utilised.	**Limited**	**2**
Crisis / emergency /relapse plans and hospital passport in place as appropriate, are person centred, routinely used and reviewed.	**Minimal**	**1**
No crisis / emergency plans required, appropriate person centred information in place.	**None**	**0**
E. Medication	**Impact**	**Rating**
Unlicensed / contraindicated use of medication. Extremely hazardous medication regime. Or, administration errors.	**Major**	**4**
Potentially hazardous medication regime without adequate reviews and monitoring. Significant compliance issues.	**Significant**	**3**
Medication reviewed but not regularly monitored; maybe with inconsistent use of 'as required' medication.	**Limited**	**2**
Small amount of medication, regularly reviewed and effectively monitored.	**Minimal**	**1**
No medication.	**None**	**0**
F. Specialist learning disability service provision	**Impact**	**Rating**
No specialist learning disability service provision available.	**Major**	**4**
Restricted specialist learning disability services available, not able to meet all identified needs.	**Significant**	**3**
Limited specialist learning disability service available.	**Limited**	**2**
Full specialist learning disability service available and accessed in accordance with identified needs.	**Minimal**	**1**
Full specialist learning disability service available but not currently required.	**None**	**0**

Determinant 3:	Communication difficulties and reduced health literacy	
Health Inequality Indicators		
A. Poor bodily awareness, pain responses and communication support	**Impact**	**Rating**
Major restrictions of bodily awareness, pain responses. Needs very difficult to discern.	**Major**	**4**
Significant restrictions of bodily awareness and pain responses and inadequate support to identify needs.	**Significant**	**3**
Some restrictions of bodily awareness and pain responses with limited support to recognise needs.	**Limited**	**2**
Some restrictions of bodily awareness and pain responses but appropriate support to help identify needs.	**Minimal**	**1**
No identified difficulties with bodily awareness and pain responses.	**None**	**0**
B. Communicating health needs to others	**Impact**	**Rating**
Major restrictions to person's ability to communicate about their health. No support in place.	**Major**	**4**
Despite support, there are significant restrictions to person's ability to communicate with others regarding their health.	**Significant**	**3**
Notable restrictions with the person's ability to communicate about their health.	**Limited**	**2**
Minimal restrictions with the person's ability to communicate about their health with others but appropriate support in place.	**Minimal**	**1**
No identified restrictions with the person's ability to communicate about their health.	**None**	**0**
C. Carers ability to recognise expressions of need and/or pain	**Impact**	**Rating**
Major difficulties with the ability of those providing support to recognise pain / distress.	**Major**	**4**
Significant difficulties with the ability of those providing support to recognise pain / distress.	**Significant**	**3**
Consistent difficulties with the ability of those providing support to recognise pain / distress.	**Limited**	**2**
Occasional difficulties with the ability of those providing support to recognise pain / distress.	**Minimal**	**1**
No identified restrictions with the ability of those providing support to recognise pain / distress.	**None**	**0**
D. Carers ability to respond to emerging health problems	**Impact**	**Rating**
Major difficulties related to the ability of those providing support to respond to emerging health problems.	**Major**	**4**
Significant difficulties related to the ability of those providing support to respond to health problems.	**Significant**	**3**
Consistent difficulties related to the ability of those providing support to respond to emerging health problems.	**Limited**	**2**
Occasional concerns related to the ability of those providing support to respond appropriately to emerging health problems.	**Minimal**	**1**
No identified concerns regarding the ability of those providing support to respond to emerging health problems.	**None**	**0**
E. Understanding health information and making choices	**Impact**	**Rating**
Major restrictions related to the person's capacity to access and understand health information and make choices.	**Major**	**4**
Significant restrictions related to the person's ability to access and understand health information.	**Significant**	**3**
Consistent difficulties related to the person's ability to access and understand health information and make choices. With good support can make some decisions.	**Limited**	**2**
Some restrictions related to the person's ability access and understand health information but with good support they are able to make choices.	**Minimal**	**1**
No identified restrictions related to the person's ability to access and understand health information and to make choices on the basis of these.	**None**	**0**

Determinant 4:	Personal health behaviour and lifestyle risks such as diet, sexual health and exercise	
Health Inequality Indicators		
A. Diet and hydration	**Impact**	**Rating**
Major concerns about eating and drinking which place the person's safety and well-being at imminent risk.	**Major**	**4**
Restrictions to healthy eating and drinking which compromise the person's long term safety and wellbeing. Little support to address these issues.	**Significant**	**3**
Some notable difficulties maintaining healthy eating and drinking. Some support in place to address these.	**Limited**	**2**
Relatively minimal restrictions to healthy eating and drinking.	**Minimal**	**1**
No restrictions to healthy eating and drinking.	**None**	**0**
B. Exercise	**Impact**	**Rating**
Major restrictions related to appropriate physical activity / exercise putting safety and well-being at risk.	**Major**	**4**
Significant lack of engagement in physical activity / exercise.	**Significant**	**3**
Some restrictions engaging in healthy regime of physical activity / exercise.	**Limited**	**2**
Few concerns related to the person's engagement in physical activity / exercise.	**Minimal**	**1**
No restrictions related to engaging in healthy regime of physical activity / exercise.	**None**	**0**
C. Weight	**Impact**	**Rating**
Major concerns about the person's ability to achieve / maintain an appropriate weight, placing them at risk of serious health problems.	**Major**	**4**
Significant difficulties achieving / maintaining appropriate weight.	**Significant**	**3**
Notable difficulties / restrictions on ability to achieve / maintain an appropriate weight.	**Limited**	**2**
Some difficulties achieving / maintaining an appropriate weight.	**Minimal**	**1**
No difficulties maintaining appropriate weight.	**None**	**0**
D. Substance use	**Impact**	**Rating**
Dependence on drugs, alcohol, or other harmful substances.	**Major**	**4**
Harmful use of drugs, alcohol, tobacco or other substances.	**Significant**	**3**
Hazardous use of drugs alcohol, tobacco or other recreational drugs but no evidence of actual harm at this stage.	**Limited**	**2**
Largely safe use of alcohol. No use of recreational drugs.	**Minimal**	**1**
No harmful use of alcohol. No use of other substances.	**None**	**0**
E. Sexual health	**Impact**	**Rating**
Very high risk sexual behaviours (may be consensual or not). Sexual abuse or sexual offending.	**Major**	**4**
Unsafe and risky sexual behaviours (may be consensual or not).	**Significant**	**3**
Inappropriate sexual behaviours (may be consensual or not) increasing vulnerability.	**Limited**	**2**
Healthy (consensual) sexual behaviours. Sexually isolated.	**Minimal**	**1**
No hazardous sexual behaviours.	**None**	**0**
F. Risky Behaviour / Routines	**Impact**	**Rating**
Major health implications related to presentation of severe behavioural disturbance.	**Major**	**4**
Behaviours / routines have significant impact on health status.	**Significant**	**3**
Behaviours / routines have notable impact on health.	**Limited**	**2**
Behavioural presentation has minimal impact on health status.	**Minimal**	**1**
No presentation of risky behaviours / routines.	**None**	**0**

Determinant 5:	Deficiencies in access to and the quality of healthcare and other service provision	
Health Inequality Indicators		
A. Organisational barriers	**Impact**	**Rating**
Organisational barriers causing major restrictions completely preventing access to services. No reasonable adjustments are in place.	**Major**	**4**
Organisational barriers causing significant restrictions in access to services. Limited evidence of reasonable adjustments being made.	**Significant**	**3**
Organisational barriers causing consistent restrictions in access to services. Reasonable adjustments are limited and inconsistent.	**Limited**	**2**
Organisational barriers causing occasional restrictions in access to services. Reasonable adjustments are in place but may have some limitations.	**Minimal**	**1**
No organisational barriers causing restrictions in access to, services. Full reasonable adjustments are in place.	**None**	**0**
B. Consent	**Impact**	**Rating**
Consent or best interest process not in place or not being implemented.	**Major**	**4**
Consent or best interest processes in place but being ignored or wrongly applied.	**Significant**	**3**
Consent and best interest processes in place and being applied but with consistent lapses of rigour.	**Limited**	**2**
Consent and best interest processes in place and generally being applied effectively, with occasional lapses.	**Minimal**	**1**
Consent and best interest processes are robust and rigorously applied.	**None**	**0**
C. Transitions between services	**Impact**	**Rating**
Complete breakdown in transition arrangements between services.	**Major**	**4**
Regular and significant breakdown in transition between services.	**Significant**	**3**
There are consistent difficulties with transition between services.	**Limited**	**2**
Transition between services is successful, given appropriate additional support.	**Minimal**	**1**
Transition between services is successful and well-coordinated, with no additional support required.	**None**	**0**
D. Access to and quality of health screening / promotion	**Impact**	**Rating**
Major restrictions in the quality of, or access to, health promotion / screening.	**Major**	**4**
Significant restrictions in the quality of, or access to, health promotion / screening.	**Significant**	**3**
Some limitations in the quality of or access to health promotion / screening.	**Limited**	**2**
Minimal restrictions in the quality of, or access to, health promotion / screening.	**Minimal**	**1**
No identified restrictions in the quality of, or access to, health screening / promotion.	**None**	**0**
E. Access to and quality of primary / secondary care	**Impact**	**Rating**
Major restrictions in the quality of primary / secondary care.	**Major**	**4**
Significant restrictions in the quality of primary / secondary care.	**Significant**	**3**
Some restrictions in the quality of primary / secondary care.	**Limited**	**2**
Minimal restrictions in the quality of primary / secondary care.	**Minimal**	**1**
No identified restrictions in the quality of primary / secondary care.	**None**	**0**
F. Access to and quality of non- health services	**Impact**	**Rating**
Major restrictions in the quality of person centred non-health services.	**Major**	**4**
Significant restrictions in the quality of person centred non-health services.	**Significant**	**3**
Some restrictions in the quality of person centred non-health services.	**Limited**	**2**
Minimal restrictions in the quality of person centred non-health services.	**Minimal**	**1**
No identified restrictions in the quality of person centred non-health services.	**None**	**0**

The Health Equalities Framework (HEF): An outcomes framework based on the determinants of health inequalities. The Complete Practitioner's Guide

The HEF was developed by D Atkinson, P Boulter, C Hebron and G Moulster from the UK Learning Disability Consultant Nurse Network with commissioned software development by J Brown of Smart Outcomes.

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