# Targets and Indicators in Health and Social Care in Scotland

**A Review** 

**Professor Sir Harry Burns** 





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#### **Foreword**

The National Review of Targets and Indicators for health and social care came about following a commitment by the Scottish Government to ensure that its approach to targets will be outcomes based to give the best possible care according to need. It is also linked to the National Clinical Strategy and continued integration which focus on improving the outcomes for patients, supported people and carers, and shifting the delivery of care from hospitals to the community.

Scotland has highly challenging targets for public services and there is wide recognition that targets for the NHS have driven improvements by transforming waiting times for patients and improving safety. Targets have an important place in the NHS and there are certain standards, such as the 4 hour Accident & Emergency target and cancer care targets which patients and carers have the right to expect.

This review was asked to look at how targets and indicators for health and social care align with the Government's strategy for the future of NHS and social care services and support the best use of public resources.

From the outset the review was charged with working with people using services, carers, staff professional bodies, and providers to ensure targets and performance indicators lead to the best outcomes for people receiving care and support, whether in hospital, primary care, community care or social care services.

I have tried to do this by engaging with a variety of groups and individuals including the Health and Social Care Alliance representing disabled people and those living with long term conditions, the Scottish Independent Living Coalition seeking the same level of freedom, choice, dignity and control as other citizens at home, work and the community for those living independent lives, the Health and Social Care Benchmarking Network improving the provision of adult care services in Scotland, the Scottish Partnership for Palliative Care working to improve the experiences of people living with declining health, death, dying and bereavement, NHS Chairs, NHS Chief Executives, Integration Joint Board Chairs and SOLACE, Scottish Workforce Governance Committee, Scottish Partnership Forum, clinical psychologists, Information Services Division of National Services Scotland, the Chair of the National Performance Framework review and the Chair of the Cancer Waiting Times review.

I have been supported by an Expert Group made up of people using social care services, patient representatives, clinicians, professional bodies, housing and carers representatives, Scottish Government senior officials and scrutiny bodies. There may be different views taken by different members of the Expert Group, but I am responsible for this report and the views expressed in it are my own. I thank the members of the Expert Group for their support and comment on the direction of travel.

I would also like to thank the members of a short life Working Group comprising representatives from the Population Health, Health and Social Care Integration, and Performance and Delivery Directorates of the Scottish Government and COSLA for the support they have provided to me and the Expert Group during this process.

# **Harry Burns**

# Why is this review taking place?

- 1. A target is a way of expressing the priority of an organisation. Setting a target lets members of the organisation know what is expected of them in terms of delivery of a service to the public. Indicators show how an organisation is progressing in pursuit of its aims. Together, they let citizens know what to expect of the organisation. Public sector organisations such as government departments, local authority services and health boards have their own management and accountability structures and yet they are all part of a complex system of organisations and services which must work effectively together if they are to deliver better outcomes for citizens.
- 2. Experience with existing targets and indicators has been positive in many respects. Significant improvements have been seen in many aspects of health and social care following their introduction. However, frontline staff and managers have often expressed frustration at the way in which targets have affected their priorities and there is a perception that a more collaborative approach to setting the agenda for public services might lead to better outcomes.
- 3. In reviewing existing targets and indicators for health and social care, this report considers first what the policy framework for public sector bodies tells us about the aims and objectives of the health and social care system. Secondly, it reviews the evidence as to how we might develop targets and indicators as effective measures of progress towards those objectives. Finally, it suggests how existing targets might become more effective in ensuring progress is made in transforming health and wellbeing in Scotland. Central to this recommendation is the concept that methods for improving delivery of services should be designed and implemented jointly by those who deliver services, those accountable for service delivery and those citizens who make use of those services.
- 4. Before effective targets can be set, it is necessary to be clear about the overall objectives of this complex system, the methods by which those objectives will be delivered and the information that can be used to measure progress towards those objectives.

# What are we trying to achieve?

5. The health and social care system in Scotland is shaped by Government and Local Authorities. The Scottish Government's overarching policy priority for Scotland¹ has been articulated in its Purpose which is "to focus government and public services on creating a more successful country, with opportunities for all of Scotland to flourish through increasing sustainable economic growth." The twin goals of tackling inequality, in all its manifestations, and boosting competitiveness have been identified by the Government as key to the delivery of its purpose. Local government is elected to deliver local priorities and sometimes those priorities might conflict with those of central government. Since the Health Service is under the control of the

Scottish Government and many other services which have a direct impact on wellbeing are under the control of Local Government, it is important that the targets and indicators are seen by both sides as supportive of progress towards a better society.

- 6. Achieving a flourishing population with the capacity to create sustainable, inclusive growth requires considerable engagement of the health and social care system. Improving health and reducing inequalities in health and life expectancy across socioeconomic groups in Scotland is key to achieving the purpose. Boosting competitiveness requires a healthy, educated and engaged workforce. These tasks require all of Scottish society, including government, local authorities, health boards, third sector and voluntary bodies to work together to understand how the complex systems which determine wellbeing and success across the life course can be modified to improve outcomes.
- 7. An important word in the purpose statement is "flourish." The dictionary definition of flourish is to "grow or develop in a healthy or vigorous way, especially as the result of a particularly congenial environment." Flourishing is also a concept in positive psychology. Corey Keyes, an American researcher defined flourishing as "the product of mentally healthy adults having high levels of emotional well-being; they are happy and satisfied; they tend to see their lives as having a purpose; they feel some degree of mastery and accept all parts of themselves; they have a sense of personal growth in the sense that they are always growing, evolving, and changing; finally, they have a sense of autonomy and an internal locus of control, they chose their fate in life instead of being victims of fate."
- 8. In essence, people are flourishing when they have a combination of high levels of mental health which is reflected in emotional well-being, psychological well-being, and social well-being. Achieving a flourishing population, therefore, demands not just that we improve physical health but also that all individuals and communities feel supported to grow in emotional, psychological and social wellbeing.

# The Challenge

- 9. Scotland has long standing problems of health and wellbeing. In a comparison of life expectancy trends in 16 Western European countries, Glasgow Centre for Population Health showed that Scots had the lowest life expectancy of all the countries studied<sup>2</sup>. It was not always so. The study gathered data as far back as 1861. For most of that time, the life expectancy of Scots was comparable with our neighbours. It is only in the past few decades since around the 1960s that we have drifted to the bottom of the Western European league.
- 10. Closer examination of the data shows that much of the problem is associated with socioeconomic inequality. The life expectancy of affluent Scots has increased at a much faster rate than that seen in the most deprived areas. As a result, growth in average life expectancy across the population has slowed. Inequality can, however be defined in ways other than life expectancy.

Inequality in terms of opportunity to flourish due to the way society causes disability for certain groups, for example, is a real risk requiring public services to be assiduous in assessing and meeting need for support to disabled citizens.

- 11. Widening socioeconomic inequality has been attributed by some to industrial policy in the latter half of the 20<sup>th</sup> century. Parts of Scotland experienced considerable loss of jobs in traditional industries. At the same time individuals were being uprooted and moved to new towns and districts as post war housing reforms were taken forward. Social cohesion was eroded. Whatever the reason for widening inequality, it is clear that without efforts to narrow the spectrum of socioeconomic status, improvements in our life expectancy will be slow.
- How we might achieve this aim is not entirely straightforward. Conventional thinking might suggest that, since heart disease and cancers are the commonest causes of death, reducing smoking, improving diet and encouraging exercise should be the main strategies used to improve wellbeing in Scotland. Undoubtedly these interventions are important and efforts to achieve better heart health and cancer prevention should be intensified. However, the causes of inequality in life expectancy are more complex. Deaths from heart disease and cancers mostly occur in the elderly and it has been shown that inequality in mortality is widest in age groups which are younger than those most affected by heart disease and cancer. The causes of greatest inequality in younger people are not principally heart disease and cancer but deaths due to drugs, alcohol, suicide, accidents and violence. If we are to improve life expectancy and wellbeing in Scotland up to levels comparable with the rest of Western Europe, we need to do more than provide smoking cessation services, important as they are. The causes of inequality require attention to the emotional, psychological and social needs of people as much as they require attention to the causes of illness.
- 13. Current thinking on transformational change for wellbeing would support us adopting a life course approach. WHO Europe, in 2015, advocated such an approach in its Minsk Declaration<sup>3</sup>. This document outlines a set of actions, which might be taken by governments in their efforts to deliver the Sustainable Development Goals. It states that: "a life-course approach for health and wellbeing builds on the interaction of multiple promotive, protective and risk factors throughout people's lives. This approach adopts a temporal and societal perspective on the health of individuals and generations, including intergenerational determinants of health. A life-course approach is an investment in health and well-being. The adoption of the life-course approach across the whole of government would improve health and well-being, promote social justice, and contribute to sustainable development and inclusive growth and wealth in all our countries." Essentially, such an approach involves acting in early life and at major transitions to support individuals.
- 14. The critical importance of early years in determining future wellbeing is particularly identified by WHO.

"The earliest years of life set the tone for the whole of the lifespan. A child that is cared for, nurtured and stimulated, appropriately fed and protected

early in life, grows into an adult with greater life chances, better cognitive and physical development, superior educational achievement, and greater productivity. Investment in early childhood development, and protection against toxic stress and dangerous environmental exposure at critical points of development are among the most cost effective policy choices available to governments."

15. This review argues that, if we are to deliver the policy objectives of supporting the population of Scotland to flourish through reducing inequality and improving wellbeing, we need to create a society which allows all individuals, regardless of ability, ethnicity, economic or social status to be resilient, be in control of their lives and feel they have a sense of purpose. Individuals with these characteristics are less likely to fail in education, engage in offending behaviour, be unemployed and more likely to adopt healthy behaviours. If these outcomes are indeed the policy context for this review of targets and outcomes, we need to consider carefully if our present approach is fit for purpose.

# Targets and indicators in the public sector

- 16. The concept of managing public services by use of targets emerged in the 1980s. Government set about improving the efficiency of public services by making them more business-like. This new approach, known as New Public Management, focussed on "customer service" which was defined as the "...centrality of citizens who were the recipient of the services or customers to the public sector. "Citizens" became "customers" of public services.
- 17. New Public Management allowed experimentation with decentralized service delivery models, giving local organisations more freedom in how they delivered programs or services. In England, and, for a short time, in Scotland, market like structures were set up to create competition in health care between the public and the private sector. The health service became an internal market, with self-governing Trusts, GP fundholding and commissioning of services for example. Critics of such systems saw them as ways to distance Ministers from responsibility for difficult decisions while proponents saw them as ways of increasing efficiency while improving "customer service."
- 18. Other important themes for New Public Management were "financial control, value for money, increasing efficiency, identifying and setting targets and monitoring of performance". In particular, performance was assessed using audits, benchmarking and performance evaluations.
- 19. While it can be argued that targets are necessary to set direction for an organisation and motivate staff to achieve the goals of the business, some management scientists have suggested that targets are the remnants of a discredited command and control system which demotivates staff and causes them to focus on the wrong aspects of their work. The challenge in this review is to suggest a process of designing targets and indicators in association with those who deliver services and those who use them. In that way, frontline staff

can be encouraged to innovate and, through working with those who use services, find ways of improving them more effectively.

# The benefits and problems of targets

- 20. Studies of the impact of targets usually describe two issues. Firstly, there is little doubt that they produce improvements in the process that has been targeted. Secondly, most studies also identify problems. For example, in a review of two target setting policies, Elkan and Robinson (1998)<sup>4</sup> examined the effectiveness of targets in the delivery of two UK Government policies: the 1992 Health of the Nation strategy and the 1990 General Practitioners' Contract. They concluded that the introduction of both policies was accompanied by improvements in performance. They also found that targets caused a number of problems. They felt that targets tended to focus action on those things that were most easily measured, that they could foster complacency on the part of providers who have already achieved target levels of performance, and defensiveness on the part of those performing badly. They felt that national targets might adversely affect local priorities. They also suggested that targets might widen inequalities in health by being unrealistic and unattainable in deprived populations. Their paper concluded that a target-setting approach to improving the quality of care must be based on the appropriate use of indicators, and must take account of differences between more and less advantaged sections of society.
- 21. In 2010, The Kings Fund<sup>5</sup>, examining the impact of targets in the NHS in England concluded: "enforced targets do appear to have been successful in improving aspects of NHS performance, particularly in relation to waiting times, but there is some evidence of unintended consequences for example, distortion of priorities or neglect of other non-targeted activities. However, it is important to recognise that such unintended consequences may not be the inevitable result of targets in themselves, but rather of the way in which those targets were designed or implemented.
- 22. This Kings Fund report refers to targets in the NHS and we are concerned about how to manage a whole system of collaborating agencies which have manifestly different cultures. The danger of targets having unintended consequences is probably magnified when different agencies are jointly responsible for delivering them. This is an issue which requires careful consideration.

# Design and implementation of indicators and targets

- 23. The theme that the effectiveness of targets depends on how they are designed and implemented was discussed in a paper published by the Health Foundation in 2015<sup>6</sup>. Berry and colleagues suggested that the design of any new target needs to be **pragmatic**, **collaborative and iterative**.
- 24. Ideally, targets should focus on achieving agreed outcomes. However, where processes are essential to the delivery of desired outcomes, pragmatism is

- necessary. The earlier a patient with cancer is diagnosed and treated, for example, the greater the likelihood of good outcome. Waiting time for treatment, therefore, is a pragmatic indicator of the probability of better treatment outcome.
- 25. Collaboration/coproduction in design is essential to ensure that targets are relevant to and supported by those who have to deliver them and those who are affected by them. Bodenheimer and Sinsky (2014)<sup>7</sup> argued that constructive engagement with staff should be seen as a way of preventing burnout. They proposed that the Triple Aim of improving population health, improving care and services delivered to the public and improving efficiency of services should become a Quadruple Aim. The fourth limb of this aim would be to improve the work life of health and social care workers by allowing them to be involved in how the indicators were implemented.
- 26. Public sector staff are motivated to deliver best care to those they serve. They are more likely to feel valued and empowered if they have been involved in shaping indicators and targets and are given responsibility and recognition for developing new approaches and using them to improve care.
- 27. Iteration, continuous examination of the effectiveness of indicators and targets is crucial. No target is likely to be perfect, and frontline staff should be involved in regular reviews to ensure that they remain appropriate, that lessons are being learned and spread to other areas of the service and that problems are dealt with and benefits maximised.
- 28. This point about iteration is of great importance for this present review. Targets have political significance. Berry and colleagues suggested that, for NHS England: "the existing suite of targets needs to change, but this will require strong political leadership and should be gradual not wholesale. Removing targets without a credible alternative in place is not without risk, but there is a strong case for clarifying how the existing targets fit within the vision for wider transformations in care. Permission to change the amount of managerial and political capital invested in targets is needed in order to rebalance the current, disproportionate focus on delivering against targets over other priorities. The totemic status of targets means strong political leadership from the centre of government will be necessary to make such changes stick."

# The need for systems thinking in design

29. Ensuring that all individuals have an opportunity to achieve their full potential in life requires a common sense of purpose across the public sector. In working together to achieve that aim, the public sector becomes a complex system. In such systems, action taken in one part can have significant and unanticipated consequences in other parts of the system. "Systems thinking" describes the processes of developing an understanding of a system by examining the linkages and interactions between the elements that compose the entire system. To achieve a coherent strategy to deliver improvement we need to think through the probable impact of all the different activities that might occur across the various organisations participating in the system. An important conclusion of

seeing health and social care as a complex system is the need to focus on indicators before setting targets.

# Indicators come before targets

- 30. A target defines a goal which a system is supposed to reach. Not reaching it is often seen as a failure of the system which can attract criticism. Efforts by the organisation to avoid failure might involve defensive action which could be unhelpful to citizens dealing with the organisation.
- 31. However, experience suggests that with complex systems, what can be measured is often not sufficiently detailed to allow for meaningful performance monitoring. The result is often oversimplification of the system to a set of numbers which do not provide adequate information to allow improvement of the outcomes of the complex system. As a result, opportunities for performance improvement across the whole system are often missed.
- Intermediate outputs only tell you if the system is malfunctioning. If a target has 32. not been met, it is a clear indicator that the system did not perform, but nothing can be said about what part of the system failed or why. Nor can such data help you identify where action to correct or improve the system is needed to establish or restore performance. One example might be the 4 hour waiting time target for patients attending A&E. Hospitals are criticised for failing to make this target. However, rather than being a measure of inefficiency within A&E, the 4 hour target may reflect problems elsewhere in the flow of unscheduled care patients. Current evidence suggests that failure to meet the 4 hour target is most frequently due to high levels of bed occupancy within hospitals. Patients who have to be admitted are increasingly having to wait for an empty bed. In recognition of this fact, New Zealand - which has a six hour target for A&E waiting - has made the target one for the whole hospital, not just the A&E department. Better bed management within the whole hospital may be the solution to unacceptable waiting times in Emergency Departments. Targets tend to focus attention of only one element of a system and may divert attention away from other areas requiring attention which, as well as being other aspects of the hospital setting, includes available care and support within the community. Evidence is very clear, patients who wait more than 4 hours have poorer outcomes and this target needs to be kept but it should be seen in the context of other determinants of patient flow.
- 33. A similar problem exists in attempts to understand the complex social, cultural and economic determinants which influence health and wellbeing. If we are to make progress in narrowing health inequalities, we need to understand the complex links in the system that allow social or economic inequity to lead to health inequality. Such understanding is clearly essential to allow agencies to take preventative action.
- 34. Indicators identify a direction of travel for the system. The task of the organisation is to ensure that what is being measured is moving in the right direction as identified by the indicator. That direction may have a target

associated with it but the principal task is to ensure steady progress towards the target, not necessarily achieve it right away. For example, the proportion of adults meeting the latest physical activity recommendations in 2015 was 63%. The task for health and social care institutions might be to design a number of services which would support more adults to be physically active over the coming years. It might be reasonable to set a target of, say 70% of people being active by 2020. However, we need to be confident that we can accurately measure physical activity and that we have a credible method for achieving change, if we are to set such a target. In the meantime, the indicator sets a direction for physical activity in Scotland.

- 35. What is clear is that the usefulness of indicators and targets depends on how they are set, what is measured and how the data is used. If they are to be useful, they need to be based on timely, accurate information which allows the workforce to design and test progressive improvements to support delivery of targets and indicators they have had a say in shaping.
- 36. Not all the targets and indicators currently in use across health and social care in Scotland fulfil these conditions. However, many are suitably aspirational and with appropriate staff and public involvement would allow continuous improvements to be made. Too often, however, when targets are set beyond the capacity of the system to cope, organisational attention becomes fixed on meeting deadlines and opportunities to improve processes and outcomes across the whole system are missed.

#### Principles for designing indicators and targets

- 37. If we are to adopt a rational system of targets and indicators for health and social care, we need to agree the aim of the system, the outcomes which would deliver that aim, and we need to understand what action could be taken that would deliver those outcomes. Once we know the drivers of improvement, we can then identify the indicators that would reassure us that improvement is taking place. Once the indicators are known to provide useful information, targets for improvement might be set.
- 38. As already described, any new indicators should be pragmatic, coproduced with staff and those who access the services they measure. They should be subject to regular review to ensure they remain relevant. They should provide information on the whole performance of a system and not be based on a snapshot of one aspect of that system. Such snapshot can only tell whether a target is being reached. They cannot provide information as to why the system might not be reaching the target.

# Targets, indicators and information for improvement

39. It is important to be explicit about what this review will NOT consider. If indicators set a direction of travel for a system and targets indicate that a goal is being reached, improvement processes are the actions which are taken to allow

the system to move in the appropriate direction. These can involve many tests of change in pursuit of continuous improvement. Health and social care staff in Scotland have had extensive experience of these methods in the Scottish Patient Safety Programme and the Early Years Collaborative. It is beyond the scope of this review to consider the detailed processes by which an improvement approach might deliver the indicators. However, targets and indicators by themselves will not guarantee appropriate action across the system. A method for achieving change should be explicit. For example, one current target is: "improve children's services." No one could argue that this is a desirable target. However, if we do not have an understanding as to what constitutes improvement and a method by which they are to be improved, then progress will, at best, be slow.

- 40. This review, therefore considers the relevance of current targets and indicators to the overall objective of achieving a healthier, flourishing Scotland. The methods for improvement which might produce progress need to be designed and implemented by the wider system of staff and people using services.
- 41. Nor is it possible for this review to consider the information required by local organisations in the management of services. Some responses to this review suggest that it is expected that it will recommend reduction in the amount of data collected by public sector organisations. Such reductions might come about as a result of new approaches suggested by this review but that will be for local decision.

#### The current landscape

- 42. In addition to the priorities of government, local communities have their own concerns, expressed through local democracy when electing Local Councils. Councils play a critical role in the design and delivery of services that contribute to the improvement and maintenance of health and wellbeing. They have an important role in providing opportunities for exercise and recreation. They provide education, social care, housing, and a range of other services which are essential to wellbeing. Economic growth, and particularly growth which is shared equitably, requires a healthy, educated and engaged population. The contribution of the health and social care system to achieving this aim might be defined as ensuring that the people of Scotland live longer, healthier, more fulfilled lives.
- 43. Health Boards organise and deliver health care in their areas. Together with local authorities, they are embarked on an effort to integrate services. The Public Bodies (Joint Working) (Scotland) Act 2014 established Integration Authorities to plan and deliver services for their area under the management of Integration Joint Boards. Integration Authorities plan and deliver services in partnership with local communities and a range of organisations from the third and independent sectors.
- 44. As already indicated, coproduction of change is a core principle of designing better indicators of progress. The Third Sector comprising community groups,

voluntary organisations, charities, social enterprises, co-operatives and individual volunteers - has an important role in helping public bodies improve services. These bodies are best able to reflect the experiences of people who come into contact with health and social care and future design of targets and indicators needs to involve the Third Sector fully in the process

- 45. Government, Local Authorities, Health Boards, Integration Joint Boards and the Third and Independent Sectors must work together to design and deliver services in better ways to deliver the aim of better, healthier, longer lives for the people of Scotland.
- 46. The remit of this review is to consider the relevance to health and social care of three nationally set groups of targets and indicators. These are the National Performance Framework (NPF)<sup>8</sup> indicators, of which 30 relate directly or indirectly to health and social care, 19 Local Delivery Plan (LDP)<sup>9</sup> Standards and 23 Integration Indicators<sup>10</sup>.
- 47. The National Performance Framework indicators primarily focus on high level outcomes, for example improving self-assessed general health, improving mental wellbeing, reducing premature mortality, reducing poverty. The LDP Standards primarily focus on waiting times for scheduled, unscheduled and mental health; and volumes of intervention activity to support behaviour change smoking cessation and ABIs. The Integration indicators focus on two broad areas. These are individuals' experience of care and high level indicators of how care is being delivered, for example emergency admissions, delayed discharge, where the last six months of life is being spent.

#### Inadequacies of the present system

- 48. The present system does not, in some respects, adhere to the principles for good design of indicators and targets described.
- 49. Systems thinking is not made easy by having three separate suites of targets and indicators with different organisations accountable for delivery. This fragmentation makes it difficult to think of the public sector as a single, complex system. Organisational boundaries make sharing of data difficult and different lines of management accountability make improvement difficult.
- 50. Although there is some evidence of coproduction of targets and indicators with staff and the recipients of services for example the health and social care integration indicators, there is greater scope for coproduction. Some targets have been borrowed from other parts of the UK and many are based on good evidence that, if applied, should result in better outcomes. However, in many cases, no data is routinely collected to show outcome improvement.
- 51. There is no explicit acknowledgement of an overall aim for health and social care as the basis for the existence of indicators and targets. If a flourishing, healthy and long lived population is the aim, acknowledgement of this purpose would help engage staff and the wider population in delivery. The quadruple aim should be embraced across health and social care.

- 52. The reporting of performance should also be considered. At present, public debate tends to focus on specific parts of the system in isolation. The frequency of the publication of data is important in this respect with the indicators having weekly, monthly or quarterly publications receiving most attention and often in isolation of the bigger picture.
- 53. Accurate reporting requires appreciation of context. The social context in which some organisations have to deliver a target is significantly different from that in which other organisations have to deliver them. The social context of some groups such as disabled people or the elderly may require different indicators or different methods of analysis from those used in, for example, acute care.
- 54. The present approach has undoubtedly had many beneficial effects with waiting times for care being substantially reduced and other outcomes improved. Where countries report waiting times in A&E and for investigation and treatment, ours compare favourably with most international data. However, this review provides an opportunity for Scotland to move its performance to a new level by adopting a new approach which might encourage continuous progress in many areas.
- 55. The current groups of targets and indicators relate to several areas including work and employment, the environment, and communities. This wide range of topics reflects a highly strategic approach to societal development. In thinking through the relationships between the different dimensions of the NPF, it is clear that many of the drivers of sustainable economic growth have an impact on health and wellbeing. This review has focused on those of greatest relevance to health and social care. (See **Appendix 1**). However, the opportunity to consider a wider set of indicators which might include alternative measures of economic growth which are more relevant to population wellbeing might be considered at a future date.
- 56. To ensure people live longer, healthier lives, the health and social care system obviously requires to know it can act effectively to prevent, detect and treat illness. However, we know now that the decisions people take to maintain their health are significantly influenced by the social and economic conditions in which they live. To deliver longer, healthier lives, we need to have an effective health care system but we also need a supportive social and economic environment. In parts of Scotland, it is clear that the health benefit of improving the socioeconomic determinants of wellbeing is likely to bring greater improvements in healthy life expectancy than providing more health care. Action across the whole of society is required and the targets and indicators, if they are to be helpful, need to encourage joint working across all agencies and with all communities.
- 57. The NPF, Local Delivery Plan and Health and Social Care Integration indicators are intended to allow monitoring of progress and performance in delivering integrated services to people. These three sets of targets form the basis of this review and are defined in detail in **Appendix 1.** However, if the health and social care system is to make progress in improving outcomes, it needs to find an effective method for joint working to improve all determinants of wellbeing.

# Designing a more effective system

- 58. So far, the targets and indicators used in Scotland have been associated with significant improvements in performance. We could make the system more effective, however. Albert Einstein is credited with saying: 'we cannot expect to solve all our problems if we use the same thinking we used when we created them." We need to overhaul the system using the principles outlined in previous sections. Focusing on indicators as a means of determining progress of the system towards an outcome and coproduction of the methods by which indicators will improve by those who deliver the service, those who are accountable for its delivery and those who use the service all seem necessary if we are to achieve the best possible result.
- 59. We will not achieve a system which staff or recipients of the service feel committed to if one individual decides what should be measured. Accordingly, it would be most appropriate if, for each set of indicators, working groups were to agree what the actions most likely to improve progress were. These working groups could involve Health Boards, IJBs, Local Authorities and the Third and Independent Sector organisations. Important to the improvement process is the collaborative sharing of information as to what works in producing progress.
- 60. The assurance that explicit processes are in place, agreed by staff, managers and people who access the services, to deliver continuous improvement in indicators would resolve many of the issues of the current system.
- 61. The experience of programmes such as the early years collaborative has shown how collaboration across organisational boundaries can transform outcomes in a complex system. We should use that experience to achieve progress in delivery of a better society. To emphasise the fact that improvement is achieved when joint working is effective, the indicators have been grouped according to a life course or topic based approach.

# Comment on existing indicators and recommendations

62. Rather than comment on existing indicators and targets in the groupings in which they are published, they have been clustered into a series of themes relevant to a lifecourse approach where possible. In the spirit of paragraph 59 above, the following observations are offered for consideration as the basis for the next stages of the development of co-produced indicators and targets.

#### Indicators of children's wellbeing

63. Extensive research tells us that the period before birth and the first few years of life are critical to wellbeing throughout life. The indicators relevant to children's wellbeing are mainly part of the National Performance Framework. The most important of these indicators is the one about child poverty.

Improve children's dental health (NPF)
Increase the proportion of babies with a healthy birth weight (NPF)

Increase the proportion of healthy weight children (NPF)
Increase the proportion of pre-school centres receiving positive inspection reports (NPF)
Improve children's services (NPF)
Reduce children's deprivation (NPF)
CAMHS Waiting Times (LDP)
Early access to Antenatal Services (LDP)

- 64. These indicators are all important and provide data which tells us about year on year progress in improving markers of children's wellbeing. For example, significant improvement in children's dental health, some improvement in healthy birth weight and the proportion of children with healthy weight tells us that child health is improving. Stillbirth rate and Infant mortality have also been improving in Scotland and these are important figures that allow international comparison.
- 65. Child and family poverty is an important determinant of poor outcome. The proportion of children in Scotland living in poverty varies depending on the definitions used. Depending how it is defined, between 10% and 26% of children could be said to live with a degree of poverty. The distribution of child poverty will not be equal across Scotland and, to support action in the areas most affected by this issue, consideration should be given to reporting the incidence, using a definition agreed with Third Sector organisations working with child poverty, by local authority or HSCP area.
- 66. The most important predictor of failure in terms of poor mental health, educational failure, offending and, ultimately poor physical health is exposure to Adverse Childhood Experiences (ACEs), Studies in the US, England and New Zealand confirm that exposure to domestic violence, physical or emotional neglect, parental absence through incarceration or mental illness are strongly associated with poor outcome. The most important indicator of need for support for children is the identification of ACEs.
- 67. Outwith the framework of targets and indicators work is the Getting it Right for Every Child (GIRFEC)<sup>11</sup> programme which uses its own data collection system to help identify children in need of support. Those working with children under the GIRFEC programme collect data on 8 domains. GIRFEC asks: are children Safe, Healthy, Achieving, Nurtured, Active, Respected, Responsible and Included (SHANARRI). It is not clear how this system identifies ACEs and it would be helpful to see if there is a standard approach to identifying and managing neglect in babies. It would also be helpful if there was a coherent approach adopted in efforts to identify and manage adversity in struggling families.
- 68. Concern has been expressed about the length of time some children wait to be seen by CAMHS services. Access to the right treatment in a timescale that supports clinically effective treatment is clearly central to CAMHS. At the moment only around 1 in 3 children who require assessment or treatment are currently receiving it, and therefore it is appropriate to continue to focus on the 18 week RTT improvement standard that is in place for CAMHS. The

complexities and overlap of assessment and treatment of mental health conditions means it is appropriate to have different standards to help drive improvement and to ultimately deliver parity in effective and appropriate mental and physical health outcomes.

#### 69. Recommendations:

- a) Stillbirth rate and Infant Mortality Rate should be included in the annual reporting of children's wellbeing.
- b) For an agreed geographical area (such as local authority or HSCP), the proportion of children living in poverty should be reported annually.
- c) An information system to allow identification of exposure to adverse childhood experiences should be set up and a protocol for management of such cases should be agreed by a working group involving all parties who share responsibility for children's services.
- d) At present, concern has been expressed by some that an 18 week referral time for CAMHS is too long. Some children will need to be seen more urgently than others. Advice on the appropriate protocols for urgent referral should be agreed.
- e) Health Boards and Local Authorities should be supported with appropriate information systems to allow identification of those children and families needing support as a result of living in adverse circumstances.

# Attainment of young people

Increase the proportion of schools receiving positive inspection reports (NPF)
Increase the proportion of young people in learning, training or work (NPF)

- 70. At first sight the fact that only two of the indicators under review are related to attainment might seem inadequate. In fact, "improve the levels of educational attainment" is an NPF indicator which has not been included in this review. This indicator measures Scotland's performance against international standards as measured by the Programme for International Student Assessment (PISA) system.
- 71. While methods to improve attainment are largely directed at improving what goes on in schools, evidence suggests that exposure to ACEs and, in particular, domestic violence is a powerful predictor of educational failure. As child poverty is tackled and as exposure to ACEs is reduced, we would expect educational performance to improve. Analysing attainment by socioeconomic deprivation of areas would be an important way of measuring the impact of child poverty on

attainment. Making such an effect explicit would encourage greater efforts to improve socioeconomic circumstances of families.

#### 72. Recommendations:

- a) Existing measures of attainment describe Scotland's performance relative to international comparators. It is not suggested that this should change. Improvement in wellbeing in infants from families living in adverse circumstances should produce improvement in school attainment. Analysis of school attainment rates should routinely consider the effect of adverse circumstances arising from socioeconomic deprivation on attainment.
- b) So far as the measurement of the proportion of young people achieving positive destinations is concerned, it appears this indicator is being changed to a measure which will estimate participation over a 3 year period. This measure has been designed after wide consultation and should give a better estimate of the destinations of young people leaving school.

# **Access to Emergency Care across the whole population**

- 73. The indicators currently being collected by Integration Authorities are:
  Reduce emergency admissions to hospital (NPF)
  Accident and Emergency Waiting Times (LDP)
  Rate of emergency bed days for adults (HSCII)
  Readmissions to hospital within 28 days of discharge (HSCII)
  Percentage of total health and care spend on hospital stays where the patient was admitted in an emergency (HSCII)
  Number of days people spend in hospital when they are ready to be discharged (HSCII)
- 74. Integration Authorities are developing local objectives and plans in relation to the six agreed priorities identified in the Scottish Government's Health and Social Care Delivery Plan<sup>12</sup> (occupied bed days for unscheduled care; unplanned admissions; A&E performance; delayed discharges; end of life care; balance of care spend). As is appropriate, these plans are being developed taking into account the local context of health and social care services in their area. Some authorities are focussing on the wider journey of care and this is particularly important in dealing with patients presenting to A&E departments.
- 75. Considerable attention is paid to the performance against the LDP standard that: "95 per cent of patients to wait no longer than 4 hours from arrival to admission, discharge or transfer for A&E treatment. Boards to work towards 98 per cent." This is an important standard and should remain since there is strong evidence of poorer outcome in patients who wait longer than 4 hours to be seen, treated or discharged. However, the A&E episode is one stage in a patient's journey along the unscheduled care pathway. Some Integration Authorities report that they are collecting data on why patients are presenting to A&E and examining whether enhanced community based services, working in

association with primary care and social care including care homes might meet some patients' needs more effectively. In addition, data on the outcome for patients admitted is being collected and some Integration Authorities are developing new services with specialist assessment at an early stage for elderly patients to determine the most appropriate level of care for them, thus facilitating early discharge. At present, the evidence points to difficulties in finding beds in hospital for patients requiring admission as the main reason for waiting time breaching.

76. This approach embodies the recommendations for designing targets and objectives advocated by Berry and colleagues in that it is pragmatic, collaborative and iterative. Shared learning across Integration Authorities will allow good practice to spread and this approach to improvement should be supported. Much of the information obtained from these indicators can be collected accurately and timeously. It is suitable for a collaborative improvement approach and it appears that several areas are already working in this way.

#### 77. Recommendations:

- a) All these indicators should remain. However, A&E attendances should be seen as part of an unscheduled care journey. Information on the number of attendances at A&E, their referral pathways (GP or self referred) the length of time they spent in A&E, whether they were admitted, how long they spent in hospital and what their outcome was should be reported on regularly. Information on bed availability in hospital should be reported as a key determinant of long waits in A&E. Such data gives important contextual information on demands on Emergency Departments and the effectiveness of the whole system in managing such patients.
- b) Information on the number of patients from each GP practice attending A&E would give insight into opportunities to develop other services such as new, holistic approaches to social support or mental health support in association with primary care. It is recommended that each GP practice receives regularly information on how many of its patients attend A&E and how many self refer. As already indicated, this is already happening in some IJBs. Where numbers are significant, additional support for those practices should be considered.

#### **Healthcare indicators**

78. The effectiveness of health care in reducing premature mortality depends on preventing illness, detecting it early while still curable and providing effective treatment where possible.

Reduce premature mortality (NPF)
Detect Cancer Early (LDP)
Cancer Waiting Times. (LDP)
Dementia Post Diagnostic Support – In development (LDP)
Treatment Time Guarantee. (LDP)
18 Weeks Referral to Treatment (RTT) (LDP)
12 Weeks First Outpatient Appointment (LDP)
Early Access to Antenatal Services (LDP)
IVF Waiting Times (LDP)
Psychological therapies waiting times (LDP)

- 79. Early detection is achieved through our screening programmes which are assessed by a National Screening Committee which advises all 4 UK governments. The proportion of people invited for screening who take up the invitation is reported. This should continue.
- 80. Waiting times for treatment involve a guarantee of 12 weeks as a maximum wait for treatment and a special arrangement for cancer cases to ensure they begin treatment within 2 months of referral. In addition, there is an 18 week guarantee for referral to treatment. These guarantees have an evidence base to support them (Appendix 2). However, there are clinical implications of these guarantees. The decision to offer treatment is often not straightforward. Surgery, for example has risks as well as benefits and, where these are finely balanced, patients will often wish to defer surgery or take time to consider their position. Indeed a recommendation of this review is that there should be greater use of decision support tools to help patients decide whether or not they want surgery. Evidence suggests that many patients wish to take time to think about this decision. In those circumstances, neither an 18 week or 12 week guarantee should apply. Furthermore, it can take time to investigate complex problems, diagnoses may not be obvious and it can be perfectly sensible to delay treatment until diagnosis is secure. These guarantees, therefore, cut across clinical judgement, and can interfere with patient choice.
- 81. Another problem with a fixed target is that there is a risk that patients with less serious conditions who may be close to breaching the target are treated before patients with serious conditions whose clinical priority for treatment is greater. The guarantee, in that case, comes before clinical priority. That should not be the case. While treatment time guarantees have an evidence base and to abolish them would run the risk of unacceptable and unsafe waits returning to the NHS, they carry with them the risk of affecting the standard of care and they may impact adversely on patient choice. So far as can be ascertained, Scotland is the only country which has both an 18 week RTT and a 12 week maximum wait for treatment. The 18 week guarantee should be dropped since it brings with it the possibility of altering clinical decision making. The 12 week

guarantee, which is more likely to be applied after a clear decision to treat is finally made should be kept. However, there will always be legitimate reasons why treatment might be delayed for sound clinical reasons or by patients themselves. Given the many legitimate reasons why this guarantee is not met, it seems odd that it is legally enforceable. This seems to be a law which if not followed correctly has the potential to interfere with clinical judgement, patient choice and so do harm to patients. It would be helpful if guidance issued to Health Boards on this issue ensured that clinical issues which might delay treatment were given due priority. It would be more sensible to work across the NHS to understand better how patient flows through treatment facilities might be improved. This work is underway.

- 82. HAI and AMR targets/indicators have been extremely successful in reducing rates of C.diff and MRSA and should be part of the suite of indicators in the future. This will ensure that HAI and AMR remain a priority and continue to build upon the progress made to date.
- 83. Any set of indicators of quality in healthcare should contain a reference to and support for clinical audit. Clinicians in Scotland have a long tradition of auditing clinical practice. Most of these audits have emerged from projects set up by clinicians without formal management support. In recent decades, however, the importance for healthcare systems of ensuring high standards of clinical care means that clinical audits are more commonly centrally coordinated and funded. There are two key strands for clinical audit / data collection across NHS Scotland:

# Scottish Healthcare Audits

This current suite of nine clinical audits, which includes the Multiple Sclerosis Registry, Renal Registry, Scottish Stroke Care Audit and MSK audit, is managed and delivered by Public Health and Intelligence (PHI). These programmes collect and report only Scottish data.

#### UK Wide Audit Programmes

These are commissioned by Healthcare Quality Improvement Partnership (HQIP) on behalf of the Department of Health (DH), directed by priorities for NHS England and the Secretary of State/Ministers. The programme consists of three types of data collection – national clinical audits, clinical outcome review programmes (previously known as confidential enquiries) and Consultant Outcome publications. In total the programme delivers 50 individual clinical audits. Scottish participation in these audits has a number of potential benefits including the ability to benchmark against other nations and learn from a wider community of experience in leading improvement. In addition it offers economies of scale in delivery costs.

- 84. HQIP invite Scottish participation in these clinical audit programmes at appropriate points in the contracting process. At present Scotland have formal agreements in place to participate in 8 audits. These audits are:
  - Medical and Surgical Outcome Review Programme
  - National Mortality Case Record Review Programme

- Mental Health Outcome Review Programme: Suicide & homicide
- National Neonatal
- Maternity & Perinatal Audit
- Child Health Outcome Review Programme
- Maternal, Newborn and Infant Outcome Review Programme
- Perinatal Mortality Review Tool.

In addition through historical arrangements there are 6 clinical audits where Scottish data is collected, which include cancer and cardiac audits. However, no formal agreement exists and these are not funded centrally.

- 85. The Clinical Outcomes and Measures for Quality Improvement (COMQI) group in Scotland has proposed the development of a prioritisation process to support an Audit Programme for Scotland. This proposal was brought forward recognising the need to have a clear, open and transparent mechanism for agreeing audit commissioning and participation. The process aims to assess the current audit landscape and consider quality/standard of Scottish Healthcare Audits through an Audit of Audits.
- 86. Improving the quality of the health care experience is based on a patient feedback scoring system and this indicator has been increasing since 2010. One aspect of the health care experience which is relevant to recent discussions on realistic medicine is the issue of shared decision making between clinician and patient. A recent Cochrane review 13 of the use of decision aids in planning treatment concluded: "Compared to usual care across a wide variety of decision contexts, people exposed to decision aids feel more knowledgeable, better informed, and clearer about their values and they probably have a more active role in decision making and more accurate risk perceptions...There are no adverse effects on health outcomes or satisfaction." Such techniques are currently being assessed in Scotland and, should the assessment prove positive, they should be introduced.

#### 87. Recommendations:

- a) The current 12 week waiting time for treatment should remain. However, analysis should be carried out to confirm that Scotland's waiting times distributions continue to accord with clinical prioritisation. Consideration should also be given to taking the 18 week RTT standard out of the suite of LDP standards and for RTT to be a matter for local systems.
- b) Patient confidence in clinical advice appears to be significantly enhanced when decision support tools are used in discussion about treatment options. A trial of their use should be carried out. If the outcome confirms the positive experience reported in other studies decision support systems should be introduced across Scotland.

#### **Mental health indicators**

# Improve mental wellbeing

- 88. There are currently LDP waiting times standards for access to child and adolescent mental health services and for access to psychological therapies. As is the case with targets for physical health conditions, these should be subject to clinical prioritisation.
- 89. Further consideration of mental health indicators seems redundant in view of the recent publication of the Scottish Government's Mental Health Strategy 2017-2027. This strategy identifies 40 actions aimed at improving mental health across the life course, improving access to services, ensuring physical health in people with mental health problems, protecting their rights, and it also identifies actions aimed at developing a system of indicators for mental health services.
- 90. In particular, the service will:
  - 1. Develop a quality indicator profile in mental health which will include measures across six quality dimensions person-centred, safe, effective, efficient, equitable and timely.
  - 2. Establish a bi-annual forum of stakeholders to help track progress on the actions in this Strategy, and to help develop new actions in future years to help meet our ambitions.
  - 3. Carry out a full progress review in 2022, the halfway point of the Strategy, to ensure that lessons are learned from actions to that point.
- 91. These actions seem to satisfy the idea that indicators should be subject to regular review. The only additional point that might be made is to suggest that reporting of the incidence and prevalence of mental health problems by the Scottish Index of Multiple Deprivation (SIMD) might be a useful means of identifying the impact of other interventions aimed at improving social conditions on mental wellbeing.

# **Primary Care indicators**

- 92. The Scottish Government has expressed a view that general practice and primary care should be at the heart of the healthcare system; for those who need care to be more informed and empowered than ever, with access to the right person at the right time, while remaining at or near home wherever possible. This is located within the wider context of health and social care integration.
- 93. The lack of robust primary care data has been a significant challenge in the drive towards intelligence-led primary healthcare. The dismantling of the Quality and Outcomes Framework (QOF) and establishment of GP Clusters represents a step change in approaches for continuously improving the quality of care. This is accompanied by the development of the Scottish Primary Care Information Resource (SPIRE), to help primary care and the NHS in Scotland better plan and develop health and care services, and the expansion of Local Intelligence

Support Team (LIST) analysts located in Health and Social Care Partnerships and primary care to facilitate the use of data to improve service design and delivery, care pathways and the targeted use of resources. These initiatives provide new opportunities to develop a set of indicators that will assist in understanding the contribution of the multi-disciplinary primary care of the future to improving outcomes for Scotland's people.

#### Socioeconomic indicators

94. These indicators are attempts to measure progress on tackling inequality and, as such, are at the heart of efforts to improve wellbeing.

Improved self-assessed general health (NPF)
Improve people's perceptions of their neighbourhood (NPF)
Improve access to suitable housing options for those in housing need
(NPF)

Reduce crime victimisation rates (NPF)
Improve people's perceptions about the crime rate in their area (NPF)
Reduce the proportion of individuals living in poverty (NPF)
Reduce the proportion of employees earning less than the living wage
(NPF)

Improve the responsiveness of public services (NPF)

- 95. Experience of poverty, exposure to crime, negative perceptions of one's housing and neighbourhood will have an adverse effect on mental health and self-assessed general health. For some groups, such as disabled people, immigrants for whom English is not their native language or other groups who may feel excluded from wider society, extra efforts should be made to assess their experience since they may well have specific issues. Some of these indicators will be improved by environmental action to improve housing, clean up neighbourhoods and improve amenities in an area. However, poverty reduction is the principal task if we are to improve socioeconomic indicators. There is growing interest in the concept of "the Citizen's Wage" and The Economist has suggested in the past that "the most efficient way to relieve poverty is to give poor people money." Several studies have shown that the cost of such an intervention is outweighed by the savings to the public sector in terms of reduced demand. However, such a programme is beyond the scope of this review.
- 96. All of the indicators mentioned can contribute to a flourishing, healthy population. However, specific actions to improve them seem to happen piecemeal with different organisations trying different projects. Sharing of information on effectiveness of interventions aimed at improving self-assessed health, perceptions of crime etc. needs to happen more effectively.
- 97. Some evidence points to the responsiveness of public services as being critical to creating a sense of control in individuals struggling with socioeconomic adversity. Communities in which public services engage with people effectively to meet their needs experience transformational improvements in the type of

indicators mentioned here. There is a growing interest in several deprived communities in Scotland in this approach.

#### 98. Recommendation:

a) Scottish Government, working closely with Local Government and Health Boards, Police Scotland and other agencies should commission interventions aimed at testing new ways of meeting needs in families living in difficult circumstances with a view to assessing the cost effectiveness and transformational potential of such interventions.

#### **Environment indicators**

99. The indicators under this heading are clearly relevant to the overall aim of a flourishing, healthy population

Improve access to local green space (NPF)
Increase natural capital (NPF)
Increase the proportion of journeys to work made by public or active transport (NPF)
Increase people's use of Scotland's outdoors (NPF)
Increase physical activity (NPF)

100. Access to green space is strongly correlated to a sense of wellbeing and adults who reported their health to be good or very good were much more likely to visit the outdoors once a week than adults who reported their health to be bad or very bad. Adults living in less deprived areas were also more likely to visit the outdoors weekly than those living in more deprived areas. The Care Inspectorate has produced a document on innovative practice it has encountered in encouraging outdoor play<sup>14</sup>. It seems that appropriate strategies are in place to encourage use of Scotland's outdoors. Information on activity is taken from the Scottish Household Survey.

#### 101. Recommendations:

- a) Obtaining data on use of outdoors for physical activity by infrequent surveys has obvious limitations in terms of accuracy and expense of collection. Local authorities may be able to monitor use of their leisure facilities and, increasingly, these problems might be overcome by using digital methods to collect information on activity and where it takes place.
- b) At this time, it is likely that survey information remains our best option and no change is recommended.

# Support for behaviour change

102. Alcohol and drug problems are strongly associated with socioeconomic status and successful efforts to reduce harm will have a positive effect in reducing inequality. Available data suggests that targets for these indicators are being met. However, the action described for socioeconomic indicators should have a positive effect on individual sense of agency and control. Such action, if supported, should be assessed for its impact on the effectiveness of alcohol, drug and smoking cessation interventions.

Reduce alcohol related hospital admissions (NPF)
Reduce the number of individuals with problem drug use (NPF)
Alcohol Brief Interventions (LDP)
Drug and Alcohol Treatment Waiting Times (LDP)
Smoking Cessation (LDP)
Reduce the percentage of adults who smoke (NPF)
Sickness Absence (LDP)

#### 103. Recommendation:

a) Existing indicators should remain but opportunities should be taken to assess how interventions aimed at improvement in socioeconomic circumstances might improve indicators of behaviour change.

# **Opinion indicators**

104. Many of the health and social care integration indicators measure satisfaction with services. These indicators are measured by questionnaire every 2 years. They give insight into broad trends in satisfaction with services but are probably not useful for providing insight into the impact of efforts to improve services in real time.

Percentage of adults able to look after their health very well or quite well Percentage of adults supported at home who agree that they are supported to live as independently as possible

Percentage of adults supported at home who agree that they had a say in how their help, care or support was provided

Percentage of adults supported at home who agree that their health and care services seemed to be well co-ordinated

Percentage of adults receiving any care or support who rate it as excellent or good

Percentage of adults supported at home who agree that their services and support had an impact in improving or maintaining their quality of life Percentage of carers who feel supported to continue in their caring role Percentage of adults supported at home who agree they felt safe Percentage of people with positive experience of care at their GP practice Percentage of staff who say they would recommend their workplace as a good place to work

Proportion of care services graded 'good' (4) or better in Care Inspectorate Inspections

- 105. The involvement of people in shaping their own services is of considerable importance in improving outcomes. The indicators already in place are based on data collected by questionnaire every two years. These surveys provide robust national data on performance in important aspects of patient experiences.
- 106. These surveys tell us that, for most of the indicators, the level of satisfaction is high. However, it also appears that there is considerable variation in satisfaction levels across Scotland. The national surveys could be usefully supplemented by more focussed data collection in specific areas. For example, effectiveness of services which support people who need help to live independently seems to be variable and dependent not just on the area the person lives in but also the type of disability with which they are living. Efforts to improve those areas where satisfaction is lower require data which is current and which can be seen to improve in response to intervention. At present, patient feedback in Scotland is supported by Care Opinion, an independent website which provides a means by which people are able to provide real-time feedback directly to services about their experiences of care and engage in a dialogue with services that is focussed on improvement. The Scottish Government has supported NHS Boards to engage with this website since 2013. There are now more than 8,000 stories about people's experiences in Scotland on this site alone. Analysis of the "tags" associated with these stories has proved valuable, particularly in a local context, in identifying areas of good and poor performance and generating ideas for improvement. Analytics have now been developed that stratify this data nationally, by board, by hospital and by specific service.
- 107. As part of its Person-Centred Health and Care Programme, Healthcare Improvement Scotland has tested approaches to gathering feedback at, or shortly after, the point of care and is supporting local teams to use that feedback for improvement. HIS is also testing experience based co-design methodology, which brings groups of people who have experience of using services together with the staff who deliver those services to make improvements to services.

# 108. Recommendation:

a) Existing indicators should continue to be collected since they provide a national baseline for measuring progress locally. They should, however be supplemented by more regular assessments of service utilization and effectiveness. Methods for current and relevant data collection are being developed. A small working group to consider more effective ways of collecting data on people's views of services should be convened and a strategy for rapid, locally sensitive feedback of opinions should be developed.

#### Place of care and independent living indicators

109. Concerns about where people are looked after have been expressed in a number of reports. People who are fit for discharge should not have to remain in hospital for want of support at home. The problem of delayed discharge impacts on the unscheduled care pathway and should be seen as part of a system. Similarly, discharge to a care home of a person who was previously independent may be a reflection of the severity of the illness. It may also be a reflection of an elderly person spending too long immobilised in bed.

- 110. Collecting data on outcomes of people admitted to hospital and comparing lengths of stay might give some insight into where problems with discharge are most common. Reviewing lengths of stay for people with particular conditions might identify different practice or different capacity as causes of long stay in hospital.
- 111. In terms of support for people with care needs and falls rates, these are reflections of how well the system tries to meet needs and keep people independent. Those people living with disability which makes such support necessary should be involved in shaping the services which are so critical to independent living.

Improve support for people with care needs (NPF)
Falls rate per 1,000 population in over 65s (HSCII)

Percentage of adults with intensive needs receiving care at home (HSCII)

Number of days people spend in hospital when they are ready to be
discharged (HSCII)

Percentage of people admitted from home to hospital during the year, who are discharged to a care home - In development (HSCII)

Percentage of people who are discharged from hospital within 72 hours of being ready – In Development (HSCII)

# 112. Recommendations:

- a) Measuring lengths of stay for older people or for specific interventions could point to differences in practice across Scotland. Where such differences are discovered, areas with longer lengths of stay should learn from the better performing systems. Reporting of lengths of stay should be considered as an indicator of effective care protocols.
- b) Those responsible for delivering support to elderly and disabled people should carry out a needs assessment in their area. Disabled people report that little effort has been made to assess needs on a population basis. Disabled people should be involved in designing services to meet identified needs.

#### End of life care

Expenditure on end of life care – In development (HSCII)
Proportion of last 6 months of life spent at home or in community setting
Improve end of life care (HSCII)

113. Palliative and end of life care are often grouped together. Here Palliative Care is understood to mean the provision of good care to people whose health is in

irreversible decline, with any illness or condition, whose lives are coming to an inevitable close; they may continue to live life well, with their symptoms alleviated through good care for a period which may extend for months or even years. The care provided includes but is not limited to specialist palliative care. Palliative care includes, but is not limited to end of life care, which is about supporting people as they enter the process of dying.

- 114. At present, the indicator for improved palliative and end of life care is the proportion of the last six months of life spent at home or community setting. This indicator says little about the quality of care. In December 2015, the Scottish Government published the Strategic Framework for Action on Palliative and End of Life Care (SFA). It sets out a vision for the next five years, outcomes and ten commitments to support improvements in the delivery of palliative and end of life care across Scotland. One of the commitments in the SFA is to support improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care.
- 115. Another of the commitments relates to ehealth support for the effective sharing of end of life/Anticipatory Care Planning conversations. In this context there may be opportunities to make use of the Key Information Summary, which is currently the best available vehicle for making Anticipatory Care Plans available across services. These should arise from conversations with people about what matters to them. The commitment in the Health and Social Care Delivery Plan, published in December 2017, that all who could benefit from a Key Information Summary should have one by 2021, offers an opportunity to highlight the presence of these as an indicator of the quality of palliative and end of life care for those nearing death.
- 116. In addition, the palliative and end of life care clinical community has developed guidelines which are used as the key benchmark for good clinical practice in this area.

#### 117. Recommendations:

- a) Integration Authorities should be provided with data on the provision and quality of services for palliative and end of life care in their areas. Regular review of the impact of guidelines should take place.
- b) The Key Information Summary, or its successor, might provide a useful driver for the place of the conversations around 'what matters to you', and therefore shared and supported decision making and their recording in a shareable format.

#### **Conclusions**

- 1. Indicators and targets have been effective in improving performance in a number of areas of health and social care in Scotland. However, current thinking suggests that our present system can be improved upon in terms of its effectiveness in improving services.
- 2. Principles, which should underlie the development of guidelines and targets, have been identified. An important first principle is to understand why indicators and targets are being used. This review has assumed that the guiding principle for the use of such indicators should be the Scottish Government's purpose of allowing all of Scotland to flourish through achieving sustainable, inclusive growth. Other characteristics of effective indicators include the fact that they are pragmatic, coproduced and subject to continuing review. They should also reflect the performance across the whole system they are trying to measure.
- 3. The present system of targets and indicators is fragmented and many of the indicators do not lend themselves to effective improvement interventions. A different approach to targets and indicators is necessary.
- 4. Current indicators have been grouped according to their impact on different stages of the life course. If the aim is to improve healthy life expectancy and wellbeing of individuals, then different indicators have impact on different aspects of the life course.
- 5. Improving early life, social and economic circumstances of people living with deprivation as well as improving health and social services are all interventions which interact to increase healthy life expectancy. If an effective group of indicators, which would assist continuing improvement, are to be developed, we need to see the drivers of wellbeing as part of a complex system.
- 6. It is recommended that we move to a system of indicators and targets which allow improvements across a whole system of care to be tracked. It is important that frontline staff, managers accountable for performance and the people who use services coproduce the activities which they can then use to drive improvement.
- 7. Scottish public services are effective and efficient. A new approach to improving those services can deliver further success in comparison to many other systems.

#### **Current National Indicators**

#### **National Performance Framework Indicators**

# 1. Improve children's dental health

Over the past decade there has been an increase in the percentage of Primary 1 children with no obvious tooth decay. Latest figures for 2015/16 show 69.4% of Scottish children in Primary 1 have no obvious dental decay, compared with 54.1% in 2005/06, which is the baseline year.

# 2. Increase the proportion of babies with a healthy birth weight

The proportion of babies with a healthy birth weight (appropriate for gestational age) increased from 88.9% to 90.1% between 2001 and 2016. Over the same period, the proportion of babies born 'small for gestational age' decreased from 4.2% to 2.5%, while the proportion born 'large for gestational age' increased from 6.8% to 7.4%.

# 3. Increase the proportion of healthy weight children

In 2016 the proportion of children with a healthy weight was 70%, a decrease of 2 percentage points on 2015 (72%).

# 4. Increase physical activity

The proportion of adults meeting the latest physical activity recommendations in 2016 was 64%, an increase of one percentage point from 2015.

# 5. Improved self-assessed general health

Since the baseline year (2008) there has been little change in the proportion of adults who assess their health as good or very good. The level has fluctuated between 73% and 77% over this period, though in the last four years to 2015 has been stable at 74%.

#### 6. Improve mental wellbeing

The mean score fell from 51.0 in 2006 to 50.0 in 2008, and has remained at a similar level since (ranging between 49.7 and 50.0) as in 2015.

# 7. Reduce premature mortality

In 2016, premature mortality remained very similar to 2015, which was itself the first year-to-year increase on record. However, premature mortality is currently sixteen per cent lower than in 2006, the baseline year. Premature mortality in 2016 is at its third lowest level over the full time series

#### 8. Improve support for people with care needs

The percentage of people receiving personal care at home, rather than in a care home or hospital was decreasing, from 61.8% in 2013 to 61.3% in 2015. The 2016 figure shows an increase to 61.6%, although a change in guidance for one aspect of the measure means caution should be shown when making comparisons.

# 9. Reduce emergency admissions to hospital

The provisional figure for 2015/16 of 10,559 per 100,000 population represents a 0.4% decrease on 10,599 per 100,000 population in 2014/15.

Between 2014/15 and 2015/16, the rate of emergency admissions increased for the youngest age group (aged 0 to 4). Whereas it decreased for all age groups aged 70 and up.

# 10. Improve end of life care

There has been little change in the percentage of the last 6 months of life spent at home or in a community setting over the last 6 years. Newly published figures show that in 2015/16, 86.8% of the last 6 months of life was spent in the home or a community setting. This compares with 85.3% in 2010/11. However, the increase from 2014/15 to 2015/16 (0.5%) is the second largest increase in any one year since 2010/11.

# 11. Improve the quality of health care experience

The healthcare experience score is 82.8 for 2015/16. This is the highest the score has been since the indicator was introduced in 2009/10 and shows an increase of 4.5 from the 2009/10 figure of 78.3. Patient ratings of the quality of their healthcare experience have been improving since 2010/11.

# 12. Reduce the percentage of adults who smoke

Smoking prevalence has reduced from 28% of adults in the baseline year, 2003, to 21% in 2016. There has been a four percentage point reduction in smoking prevalence since 2012.

#### 13. Reduce alcohol related hospital admissions

The rate of alcohol-related hospital admissions in 2015/16 was 664.5 per 100,000 population. This was 9.6 per 100,000 (1.4%) lower than the 2014/15 figure of 674.1 per 100,000.

Rates of alcohol-related hospital admissions have increased significantly for both men and women since the 1980s, peaking in 2007/8. Rates have fallen by 22% since then, with a small decrease of 9.6 per 100,000 between 2014/15 and 2015/16.

#### 14. Reduce the number of individuals with problem drug use

In 2012/13, there were an estimated 61,500 people, aged 15-64 in Scotland, who were using opiates (includes prescribed and illicit methadone) and/or benzodiazepines illicitly. This compares to 59,600 people in 2009/10.

# 15. Improve access to local green space

65.4% of adults lived within a 5 minute walk of their nearest greenspace in 2016, compared to 67.2% in 2015.

# 16. Increase natural capital

The Natural Capital Asset Index was 100.9 in 2015. This suggests that Scotland's stock of natural capital in 2015 is 0.9 percentage points higher than that seen in 2000 but 0.5 percentage points lower than the 2006 base year.

# 17. Increase the proportion of journeys to work made by public or active transport

The 2016 figure of 30.6% of adults usually travelling to work by public or active transport is 0.6 percentage points below the baseline in 2006 of 31.2%. This figure has stayed relatively constant over recent years at around 30%.

# 18. Increase the proportion of pre-school centres receiving positive inspection reports

The first post-baseline sample of pre-school centres inspected accounted for 16% of all private, public and voluntary pre-school centres open at September 2013. Of those inspected 94% were evaluated as satisfactory or better in all of the three reference quality indicators, 74% were evaluated as good or better and 32% as very good or better in all three reference quality indicators. Positive criteria were not met in 6% of pre-school centres inspected.

19. Increase the proportion of schools receiving positive inspection reports The first post-baseline sample of schools inspected accounted for 16% of all publicly funded schools open at September 2013. Of those inspected 90% were evaluated as satisfactory or better in all of the three Reference Quality Indicators, 69% were evaluated as good or better and 24% as very good or better in all three Reference Quality Indicators. Positive criteria were not met in 10% of schools inspected.

The proportion of schools receiving satisfactory or better evaluations in all three Reference Quality Indicators has remained unchanged over the baseline.

**20.** Increase the proportion of young people in learning, training or work
The proportion of 16-19 year olds participating in education, training or employment
was 91.1% from 1st April 2016 – 31st March 2017 compared to 90.4% from 1st April
2015 – 31st March 2016. This is an increase of 0.7 percentage points.

#### 21. Improve children's services

94% of the local authority areas that have been inspected received a positive inspection report in the second cycle of inspections.

# 22. Reduce crime victimisation rates

The risk of being a victim of crime has decreased from 16.9% in 2012/13 to 14.5% in 2014/15. This represents a decrease of 2.4 percentage points and is 5.9 percentage points lower than the baseline year of 2008/09.

- 23. Improve access to suitable housing options for those in housing need 95.7% of homeless households were entitled to settled accommodation in 2012-13, compared to 91.0% in 2011-12 and 87.8% in 2010-11.
- **24.** Improve people's perceptions about the crime rate in their area The public perception of the local crime rate as having stayed the same or improved in the past two years was 75% in 2014/15, compared to 76% in 2012/13 and 65% in 2006, the baseline year for this indicator.

# 25. Improve people's perceptions of their neighbourhood

The percentage of people who rate their neighbourhood as a very good place to live had changed from 56.3% in 2015 to 56.7% in 2016. This also represents an increase of 5.6 percentage points from 51.1% in the baseline year of 2006.

# 26. Reduce the proportion of individuals living in poverty

In 2015/16 17% of the population was in relative poverty. This is an increase from 15% in 2014/15.

# 27. Reduce children's deprivation

The percentage of children who were in combined material deprivation and low income remained steady at 10% in 2015/16.

# 28. Increase people's use of Scotland's outdoors

48.5% of adults visited the outdoors at least once a week in 2016, a similar proportion to 2015 where 48.6% of adults visited the outdoors at least once a week.

# 29. Improve the responsiveness of public services

There has been a decrease of 0.5 percentage points in the percentage of respondents who agreed with the statement that they can influence decisions affecting their local area, from 23.6% in 2015 to 23.1% in 2016, which is the latest available data. Since 2007 (the first year these data were collected), there has been an increase of 3.5 percentage points, from 19.6%.

**30.** Reduce the proportion of employees earning less than the living wage In 2017 the proportion of employees earning less than the Living Wage was 18.4% a decrease of 1.8 percentage points on the previous year.

# Local Delivery Plan (LDP) indicators and standards

#### 1. Detect Cancer Early

The national baseline for the detect cancer early LDP standard is 23.2% (based on combined calendar years 2010 & 2011). There was a 9.2% increase to 25.5% in the percentage of people diagnosed at stage 1 for breast, colorectal and lung cancer (combined) between the baseline of combined calendar years 2010 & 2011, and 2015 & 2016.

# 2. Cancer Waiting Times

In the quarter ending June 2017, 86.9 per cent of patients urgently referred with a suspicion of cancer began treatment within 62 days of their referral. In the quarter ending June 2017, 94.8 per cent of patients diagnosed with cancer started treatment within 31 days of their decision to treat.

# 3. Dementia Post Diagnostic Support – In development

The standard is to deliver expected rates of dementia diagnosis and that all people newly diagnosed with dementia to receive a minimum of one year of post-diagnostic support and to have a person-centred plan in place at the end of that support period. In 2014/15, 43,409 patients were registered with dementia on QOF.

#### 4. Treatment Time Guarantee

In the quarter ending June 2017, 81.4 per cent of patients were reported as commencing inpatient/day case treatment within 12 weeks.

# 5. 18 Weeks Referral to Treatment (RTT)

In June 2017, 84.8 per cent of patients were reported as commencing treatment within 18 weeks.

# 6. 12 Weeks First Outpatient Appointment

As at 30 June 2017, 74.0% of patients waiting for a new outpatient appointment had been waiting 12 weeks or less.

# 7. Early Access to Antenatal Services

The standard is at least 80 per cent of pregnant women in each SIMD (Scottish Index of Multiple Deprivation) quintile will have booked for antenatal care by the 12th week of gestation. In 2015/16 the lowest performance in any SIMD quintile at the national level was 85.9 per cent.

# 8. IVF Waiting Times

In the quarter ending June 2017, 99.8% of eligible patients commenced IVF treatment within 12 months.

# 9. CAMHS Waiting Times

In the quarter ending June 2017, 80.7% of children and young people were seen within 18 weeks.

#### 10. Psychological Therapies Waiting Time

During the quarter ending June 2017, 12,028 people started treatment for Psychological Therapies in Scotland and 72.4% were seen within 18 weeks. If the data submissions had been complete it is estimated that 77.9% of patients would have been seen within 18 weeks.

#### 11. Clostridium Difficile Infections

In the year ending June 2017, the rate of identifications of CDI cases across NHSScotland was 0.28 per 1,000 occupied bed days among patients aged 15 and over.

#### 12. SAB (MRSA/MSSA)

In the year ending December 2016, the rate of SAB cases across NHSScotland was 0.32 per 1,000 acute occupied bed days

#### 13. Drug and Alcohol Treatment Waiting Times

In the quarter ending June 2017, 94.9 per cent of clients who had started their first treatment for drug or alcohol use had waited 3 weeks or less.

#### 14. Alcohol Brief Interventions

In the year ending March 2017, NHS Boards carried out 86,560 interventions, exceeding the Standard of 61,081.

# 15. Smoking Cessation

In the year ending March 2017 there were 36,502 quit attempts in the most deprived areas, 7,842 were still not smoking at three months, a 'quit rate' of 21.5%, similar to the overall Scotland quit rate of 22.6%. This is below the LDP standard target of around 9,404 three month quits in the most deprived areas.

#### 16. GP Access

In 2015/16, 91.8 per cent of people surveyed responded positively when asked about 48-hour access to an appropriate healthcare professional. In the same year, 76.4 per cent of survey responses were positive for booking an appointment with a GP more than 48 hours in advance.

#### 17. Sickness Absence

In 2016/17, NHSScotland had a sickness absence rate of 5.20 per cent.

# 18. Accident and Emergency Waiting Times

In September 2017, 93.5 per cent of patients waited less than 4 hours.

#### 19. Financial Performance

All NHS boards met their 2015/16 financial targets.

# **Health and Social Care Integration Indicators**

- 1. Percentage of adults able to look after their health very well or quite well In Scotland overall 94% of people felt they could look after their health very well or quite well in 2015/16. This ranged from 90% 96% between H&SC Partnership areas.
- 2. Percentage of adults supported at home who agree that they are supported to live as independently as possible

In Scotland overall, 84% of people agreed that they felt supported to live as independently as possible in 2015/16. This is the same level as reported in 2013/14 and varied between H&SC Partnership areas from 78% to 92%.

# 3. Percentage of adults supported at home who agree that they had a say in how their help, care or support was provided

In Scotland overall, 79% of people agreed that they had a say in how their care and support was provided, which is a 4 percentage point decrease since 2013/14. This varied between H&SC Partnership areas from 72% to 86%.

# 4. Percentage of adults supported at home who agree that their health and care services seemed to be well co-ordinated

In Scotland overall, 75% of people agreed that the services seemed to be well coordinated in 2015/16 which is a 4 percentage point decrease since 2013/14. This varied between H&SC Partnership areas from 60% to 85%.

# 5. Percentage of adults receiving any care or support who rate it as excellent or good

In Scotland overall, 81% of people rated their help, care or support services as excellent or good in 2015/16, which is a decrease from 84% in 2013/14. This varied between H&SC Partnership areas from 73% to 88%.

## 6. Percentage of people with positive experience of care at their GP practice

In Scotland, 87% of patients rated their GP practice as good or excellent in 2015/16, which is the same as in 2013/14. There was a range of 80% to 97% across H&SC Partnership areas.

- 7. Percentage of adults supported at home who agree that their services and support had an impact in improving or maintaining their quality of life In Scotland overall, 84% of people agreed that the services maintained or improved their quality of life in 2015/16, which is similar to the levels reported in 2013/14. This varied between H&SC Partnerships areas from 77% to 92%.
- 8. Percentage of carers who feel supported to continue in their caring role In Scotland in 2015/16, 41% of carers agreed that they felt supported to continue caring, which is a decrease from the 44% reported in 2013/14. This varied between H&SC Partnership areas from 34% to 59%.
- 9. Percentage of adults supported at home who agree they felt safe In Scotland overall, 84% of people agreed that they felt safe, in relation to their care and support in 2015/16. This is similar to the results from the 2013/14 survey and varied between H&SC Partnership areas from 79% to 91%.

# 10. Percentage of staff who say they would recommend their workplace as a good place to work

The percentage of staff who responded positively change from 51% in 2013 to 61% in 2014. However, it should be noted this question changed slightly between the years, with 'workplace' replacing the word 'Board'.

## 11. Premature mortality rate

Between 1997 and 2013, the rate of mortality amongst those aged under 75 years decreased by 33%.

## 12. Rate of emergency admissions for adults

Rate of emergency admissions per 100,000 population for adults. This will be based on SMR01 returns for acute hospitals, and SMR04 data for psychiatric hospitals (note that some further work will be undertaken by ISD regarding this data source).

## 13. Rate of emergency bed days for adults

Rate of emergency bed days per 100,000 population for adults. This will be based on SMR01 returns for acute hospitals, and SMR04 data for psychiatric hospitals (note that some further work will be undertaken by ISD regarding this data source).

## 14. Readmissions to hospital within 28 days of discharge

Based on the SMR01 acute hospital activity data, this rate is calculated from number of re-admissions to an acute hospital within 28 days of discharge per 1,000 population. The definition of the indicator is still being finalised and may be based on an average across GP practices in order to link directly into GP benchmarking.

## 15. Proportion of last 6 months of life spent at home or in community setting

The figure has remained at just over 90% for the last few years. Across partnership areas, the proportion of the last six months of life spent at home or in a community setting in 2012-13 varied between 88.1% and 94.7%.

## 16. Falls rate per 1,000 population in over 65s

Fall rates per 1,000 population have remained steady since 2010/2011.

# 17. Proportion of care services graded 'good' (4) or better in Care Inspectorate Inspections

The indicator will be the total number of adult care services receiving a grading of 4 or above (i.e. "good", "very good" or "excellent") on all themes as a proportion of the total number of services graded. The indicator will be updated annually and will show the latest gradings for each care service at the end of March each year.

**18.** Percentage of adults with intensive needs receiving care at home The latest figure of 61.9% for 2013 shows an increase of 1.5 percentage points compared to 60.4% in 2012 and 57.1% in 2008. It is expected that Integration Authorities will be able to continue to make progress on this.

## 19. Number of days people spend in hospital when they are ready to be discharged

The number of days people have spent in hospital when they are ready to be discharged has seen a fall from 2014/15 figures and is at a similar rate to that seen in 2013/14.

# 20. Percentage of total health and care spend on hospital stays where the patient was admitted in an emergency

The underlying data will be sourced from costed health activity data and social care aggregate data. ISD have linked all health activity and resource data that is currently available at individual level (around 70% of health expenditure). This data is available by age, by speciality, by location of care etc., so partnerships can understand emergency admissions for their population or a specific cohort.

# 21. Percentage of people admitted from home to hospital during the year, who are discharged to a care home

The data would come from SMR01, which contains fields on where people were admitted to hospital from and where they are discharged to. The information is not currently considered of usable quality, so data improvement work will be required by ISD working with NHS Boards before this indicator can be used.

# 22. Percentage of people who are discharged from hospital within 72 hours of being ready

The development of this indicator by ISD is being led by the Delayed Discharge Task Force. It requires NHS Boards to set up new methods of recording and collecting the required information, and changes to administrative systems, which is expected to take up to twelve months.

### 23. Expenditure on end of life care

The data will be sourced from costed health activity data as described above under indicator 20. The file also includes death records so it is possible to work backwards from date of death and examine people's pathway of activity and resource in the time before death. For 2015, the indicator will cost the last six months of life in an acute inpatient setting, this can be broken down by age, location of treatment, speciality level and by health and social care partnership.

## **Evidence in Support of Treatment Time Guarantees**

### Cancer

Delayed treatment for some cancers increases the risk that it will spread. There are a number of clinical studies that have looked at the relationship between longer waiting times and impact on patients. Kulkarni (2009) examined the impact of waiting for surgery for bladder cancer. Longer wait times led to a lower survival rate and that patients with less invasive disease may be at relatively greater risk through waiting. Saad (2006) and Jewett (2006) looked at the impact of patients waiting for prostate cancer and for urological cancers. Chen, King and Pearcey 2007) looked at waiting times for radiotherapy and concluded that long waits may lead to decreased survival and risk of local recurrence. Waiting times for radiotherapy should be as short as reasonably achievable.

## **Outpatients**

Currently Scotland sets a 12 week maximum wait for Outpatient referral with a 5% tolerance. Performance is at approximately the 90% level with just under 40,000 Outpatients waiting over 12 weeks and 10,000 Outpatients waiting over 16 weeks. Long Outpatient waits can delay diagnosis and treatment and can be devastating for individuals and their families. One of the most important aspects of having a relatively quick Outpatient consultation is that between one-third and two-thirds of our cancer patients in Scotland come through a standard Outpatient referral process and not the urgent cancer pathway. For example, 60% of Urological cancers, 60% of head and neck cancers and 60% of melanomas are detected at Outpatient clinics rather than through the urgent cancer pathway.

### Cardiovascular conditions

There are a number of studies that look at the link between long waiting times and patient safety in relation to cardiovascular conditions. Koomen (2001) Natarajan (2002), Rexius (2004), Talwar (2005), Sobolev (2006/2008) found that long waits were associated with potentially preventable myocardial infarction, long waits for surgery caused mortality risks for patients to increase by 11% per month after acceptance for treatment and extended delays carried significant risk of death (even for low severity patients).

### **Orthopaedics**

The number of joint replacements (hips and knees) has increased in Scotland over the course of the past 10 years. With a growing elderly population we anticipate growing demand and growing pressure on services. A number of studies have looked at the length of time waiting for joint replacement and clinical outcomes. Garbuz (2006), Davis (2008), Vergara (2011), and Desmeules (2012) found that each additional month waiting for treatment was associated with an 8% decrease in the odds of better than expected functional outcome (for Garbuz waiting longer than six months was linked to a 50% decrease in functional outcome) and that delaying treatment may result in deterioration that may not be recoverable after surgery. Patients on extended waiting times had increased pain and disability compared to those that endured shorter waits, functional capacity gain was poorer for patients who waited longer than six months for surgery. Other studies Johansson (2010), Mahon (2002), and Ostendorf (2004) looked at the relationship between pain and

functional limitation and waiting times. Interestingly there appears to be mild consensus Hoogenboom (2009) that there is some evidence indicating that functional status does not deteriorate significantly up to about six months for joint replacement surgery (though Hoogenboom also recognises that from the patient perspective there are economic and quality of life arguments for a shorter wait time than six months).

## **Condition Specific Targets in Scotland**

Some years ago the Scottish Government launched the HEAT targets for hip fracture with surgery set at a defined maximum period of 24 hours at an appropriate unit. Among elderly patients hip fractures are associated with an in hospital mortality rate of between 7-14% and profound and sometimes permanent impairment and reduction in independence and quality of life. As the elderly population increases the number of hip fractures is also expected to increase annually over the foreseeable future. Current guidelines recommend that surgeons perform hip fracture surgery within 24 hours of injury. Observational studies (Simunovic, Devereaux and Bhandari 2011) suggest earlier surgery is associated with better functional outcome and lower rates of complication and leads to shorter hospital stays and mortality. Each day beyond 24 hours increases the risk of morbidity/mortality.

The HEAT target for hip fracture was one that the clinical community in Scotland (particularly Scottish Orthopaedic and Trauma Society) embraced enthusiastically. One of the largest studies into this area was conducted by Colais et al (2015) where they study the effect of early surgery after hip fracture and one year mortality with an examination of 400,000 admissions for hip fracture. This study found that patients who underwent surgery within a two day period had a much lower one year mortality compared to those patients who waited for surgery for more than two days.

## **Ophthalmology**

Vision is a key and vital sense and lengthy waiting times for vision correction can take a very serious toll for those in need of care. From a Scottish perspective we have moved from carrying out 26,000 cataract operations per annum (approximately 12 years ago) to just under 40,000 cataract operations in 2014/15. This figure is destined to grow as we have a growing elderly population, almost all in the age bracket 60+ over the course of the next 20-30 years.

Hodge (2007), Conner-Spady (2007), Boisjoly (2010) looked at the impact of lengthy waits for cataract surgery. These studies found that amongst other things that patients who have extended waits experience more vision loss, reduced quality of life and are at greater risk of falls. Individuals with cataracts have more hip fractures and motor vehicle crashes. Long wait times are associated with decline in visual acuity in patients. Those with shorter waiting times had better vision, less difficulty and fewer symptoms prior to surgery and lower rates of accidents/hip fractures while waiting for care. There are also some studies that linked increased depression rates to lengthy waits for cataract operations and other elective procedures.

Very recently the Royal College of Surgeons urged that waiting lists were given priority in Wales. In a "surgical manifesto" published in December 2015 the RCS in Wales said that more needed to be done to tackle deteriorating waiting times which have a huge impact on individual patients. "The 26 week planned surgery targets

are not being met and instances of patients waiting over a year for knee surgery cannot be tolerated." (RCS Wales December 2015)

## **Accident and Emergency Waiting Times**

The Scottish Government has set an interim standard of 95% of patients who wait less than four hours from arrival to admission/discharge or transfer for Accident & Emergency treatment. The Scottish Government website states that although the standards are measured in the Accident & Emergency department the standard requires NHS Scotland to adopt a whole system approach to Unscheduled Care to ensure timely access to services throughout the patient's journey if the standard is to be delivered effectively.

On the Scottish Parliament website the Public Audit Committee concludes: "There is always a need clinically to balance speed of care with quality of care and we agree with Audit Scotland that waiting times in the A&E Department can be an important indicator of pressure in the health system as a whole."

One of the most important aspects of poor flow in the Unscheduled Care system is reflected in the number of patients having to spend more than 12 hours in Accident & Emergency on trolleys. The Herald (4 March 2015) reflected that in one week alone in the 2014/15 Winter more than 200 people spent 12 hours queuing on trolleys as hospitals ran out of beds. NHS Greater & Glasgow and Clyde's performance against the four hour standard at that point (January 2015) fell to 79%.

There are some mixed views on the desirability of having a four hour A&E target. The Royal College of Emergency Medicine in Scotland clearly support this target, citing cases of people becoming seriously ill with heart and respiratory problems while queuing for treatment in A&Es. However, the Nuffield Trust argues that the four hour A&E waiting time target should be downgraded as it distorts priorities. The Nuffield Trust called for a range of measures over and above the four hour A&E target to give a more balanced picture with measurement suggested for trolley waits, ambulance delays and numbers leaving A&E being seen alongside patient satisfaction surveys. All of these could add a wider whole system measurement approach to Unscheduled Care. (England followed this with more targets for A&E which were added to the existing 4 hour target.)

Plunkett (2011) examined the consequences of waiting times for emergency care to find that long delays from door to team and from team to ward were associated with increased risk of death within 30 days. This trend was across the entire spectrum of patients for those most critically ill to those who felt likely to survive.

The UK Parliament Health Committee Second Report on Urgent and Emergency Services (July 2013) found in an extensive evidence giving session that none of the witnesses argued that the four hour target should be scrapped. There was a broad understanding that it was a process measure and not a clinical quality measure. Cook (2006) found that timely care in Accident and Emergency results in better use of staff and resources and reduced mortality. The end result of reducing delays in Accident and Emergency is that patients are more satisfied and that the workforce is more fulfilled. Delays in Emergency Departments include adverse clinical outcomes, poor staff recruitment and retention and increased violence against staff. Further, a

number of polls have consistently shown that delays in Emergency Departments are one of the important areas for patients.

IMAS (NHS England) found that there is some evidence that the symptoms felt in Emergency Departments with long waiting times led to worst patient outcomes and with a 43% increased rate of death after 10 days. (Richardson 2006). Waiting for admission in A&E is also associated with significant longer hospital length of stay (boarding) on average 2.35 days longer when a patient stays in A&E for more than 12 hours (Liew and Kennedy 2003). Patients with the most severe form of pneumonia have less than a 1 in 2 chance of surviving. Those chances improve considerably if effective treatment is started early. Pine (2005) found that speed of treatment is vital for many conditions. A number of Australian studies have linked Emergency Department overcrowding and long waits with increased mortality. Sprivulas de Silva (2006).

Long waits in Emergency Departments which caused delays to treatment are clearly detrimental to patients with certain time critical conditions. There are a number of studies that show the relationship between time to treatment and adverse clinical outcomes for patients with stroke, heart conditions, fractures, sepsis, pneumonia, meningitis and critical illness (range of references drawn from a Ministry of Health paper, Australia on overcrowding in Accident & Emergency Departments August 2009).

### **Nice/SIGN Guidelines**

Close to home we have a number of Sign Guidelines and Nice Guidelines that argue for maximum waiting times for people with particular conditions. For example Sign Guideline 123 and Nice Guideline CG79 argue for quick referral and quick treatment for people with rheumatoid arthritis (between 2-4 weeks of referral).

### **Gaming and Reshuffling of Patients**

One of the arguments levied against Waiting Time targets is that they do not make good use of resources, (there is gaming/reshuffling patients on lists) and performance against waiting targets is at the expense of other activities which are not subject to targets and which have a higher clinical priority. Propper, Sutton and Whitnell (2005) found that while long waiting times have been a key issue for the NHS for many years they found evidence (contrary to popular views of clinicians) that the clinical order of priority in which patients were treated from lists did not appear to have changed and the proportion of urgent cases did not fall. There was no evidence of a decrease in several measures of quality of care as a result of the policy introduced in England to target reductions in waiting times.

## **Quality of Life and Economic Considerations of Waiting Times**

Waiting for healthcare entails some measure of pain and suffering and perhaps mental anguish and certainly some aspects of lost productivity at work and leisure. (The Consequences of Waiting, Fraser Institute, October 2013). It is entirely appropriate for clinicians to take a wait and see approach to certain medical conditions. Investigations may be deferred for appropriate reasons and immediate surgery may not always be the preferred option. Such delays are entirely justifiable based on medical indications. However, where treatment is required the severe

impacts on life that can accompany waiting for medical treatment have been well researched in medical literature.

Sampalis (2001) found that longer waits for surgery were associated with significantly reduced physical function, vitality, social function and general health prior to surgery. Patients who waited longer were also less likely to return to work after surgery. Jonsdottir (1998) found that patients waiting for surgery had dual reductions in their physical and psychological functioning in addition to increased pain while also enduring emotional hardship.

Derrett (1999) examined the consequences of the quality of life for those waiting for hip and knee joint replacement. He found that patients waiting endured significant hardship. Nearly all of those waiting for joint replacements experienced pain but for half of them pain was so severe that it resulted in substantial or serious limitation of activities. Patients waiting for prostatectomy suffer from restricted drinking of fluids, struggle with long car drives, have difficulties getting to sleep and had a generally poorer physical function.

Ostendorf (2004) studied the consequences of waiting for total hip arthroplasty. Every month of waiting was associated with an avoidable loss in health related quality of life while waiting for treatment.

The impact of waiting on mental health is also an important issue. Freeman and colleagues (2009) looked at the mental health consequences of waiting for cataract surgery. They found that in spite of the temporary nature of the visual impairment prior to surgery those with very poor visual acuity were at a much higher risk of depression than those with better visual acuity. The conclusion is that shorter waiting times for cataract surgery may reduce or shorten the duration of depression.

From a wider economic point of view the medical and personal consequences of waiting for healthcare can have a significant economic impact. While economists and labour market experts have primarily studied the explicit costs of waiting for healthcare there have been some studies in the UK such as Cullis and Jones (1986) that considered the cost of private care to the individual when lengthy waits for treatment are the norm in the NHS. There have been several studies carried out on the estimated cost of waiting for a typical elective procedure - Propper (1990) Glouberman (1991) Esmail (2012) all provided calculations for the individual cost of waiting.

An interesting study in Canada for the Centre of Spatial Economics (2008) analysed the economic cost of wait times in excess of a maximum medically reasonable wait time for treatment. The focus was limited to four procedures (joints, cataracts, heart surgery and MRI scans). The final economic cost of waiting was a substantial 14.8bn (Canadian dollars at 2008 rates). The Canadian study estimates that 32% of joint patients, 7% of cataract patients and 95% of cardiac patients needed to discontinue regular activity. From a Social Care perspective 20% of joint patients, 5% of cataract patients and 25% of cardiac patients needed a caregiver.

#### **Mental Health Standards**

The dementia post-diagnostic (pds) HEAT target (now technically a LDP Standard) underpins what is primarily a *non-clinical* post-diagnostic service offer, recognising that while there a small number of clinical interventions (meds) which can slow progression of some forms of dementia only, people with the illness can nonetheless greatly benefit from skilled human interventions – and that such interventions at an early stage of the illness can help increase the efficiency of service response to dementia overall.

The justification and rationale for the pds service offer is that if people are diagnosed at an earlier stage and receive effective, person-centred and holistic post-diagnostic support on diagnosis (or shortly after), that support can enable the person with dementia to understand the progression of the illness better, make adjustments that can improve their quality of life as the illness progresses and plan earlier for future care options. The pds offer is for a minimum of a year, over which time the person with dementia (and their family) will work with a named Link Worker to build a care and support plan that will inform future care in all settings.

The post-diagnostic service model adopted in Scotland was developed by Alzheimer Scotland based on a pilot they undertook with the Dementia Services Development Centre with 3 areas in Scotland, providing real-life enhanced interventions. The pilot collected data on what was important to people with dementia and their families on diagnosis – so as well as understanding the illness, it was areas such as peer support and maintaining connected to friends, family and community (clubs, societies, church etc). So the evidence for the target is drawn from patient feedback rather than from any published clinical research.

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