Spinal Injuries Association Submission to:

Leicester City Health & Wellbeing Scrutiny Committee Meeting- March 29 2017

Re: Leicester, Leicestershire and Rutland (LLR) Sustainability and Transformation Plan (STP) in relation to NHS Continuing Healthcare

"Individuals in receipt of ongoing or long term care through NHS Continuing Healthcare are among the most vulnerable and dependent people in our society" is how the NHS England Operating Model for NHS Continuing Healthcare (2015) describes those whose complex health care needs must be met by the NHS because their needs exceed what can be lawfully provided by a Local Authority, i.e. social care. NHS Continuing Healthcare (CHC) funding can be, and is, provided for care in individuals' own homes enabling them to continue to live in their own homes and be contributive members of their families and wider society. Those eligible for CHC funding include people with advanced degenerative neurological conditions (e.g. Parkinson's disease, motor neurone disease, multiple sclerosis), Learning Difficulties, and those paralysed as a result of a spinal cord injury.

Spinal-cord-injured (SCI) people who are in receipt of NHS CHC funding predominantly receive 'care at home' packages of care and, as a result, lead productive and socially inclusive lives. Many are young or relatively so and have, or will go on to have, families. Indeed, some SCI people in receipt of NHS CHC are in employment.

The Spinal Injuries Association (SIA) is gravely concerned by reference in the LLR draft STP of an apparent intention to implement measures to drive down local NHS Continuing Healthcare (CHC) expenditure by £29 million (STP strand 3 - Redesigned Pathways Net Savings) or ~40% from the current CHC spend of approximately £73 million per annum. There are currently approximately 1,300 of the *"…most vulnerable and dependent people…*" in LLR in receipt of NHS Continuing Healthcare funding, and these include people with paralysis as result of spinal cord injury. Matt Hampson, a high profile local figure and SIA member is one of these.

SIA also notes with concern that in LLR the CCGs plan both 'efficiency savings' and reduction in the cost of CHC 'care at home' packages in order to achieve this. This intention is clearly stated in the LLR CCGs "*Settings of Care*" policy revision, consultation on which closed on February 21, 2017: the new policy seeks to reduce the amount of money spent on providing CHC-funded care in an individual's home by comparing it to the cost of a nursing home placement, and the "*Amended Settings of Care Policy - Easy Read"* version (January 18, 2017) overtly states:

"What will change? and provides the answer *"We will spend less money on each patient*".

John Ashworth, MP for Leicester South and Shadow Minister for Health, criticised these proposals (press release February 27 2017), stating "*I am very concerned that the cost of care needed in the community setting will be more than the cap set. As a result a person could be forced to live in residential care or live at home with insufficient levels of care*". His statement went on to assert that "*this…may in fact increase financial demands on the NHS… If care packages are reduced to an unsafe level it could result in many people developing further health complications which could require hospitalisation and end up costing the NHS substantially more in the long term*".

SIA believes that to achieve the level of savings that are indicated in the draft LLR STP there would be no option but to both:

- very significantly reduce the cost of CHC 'care at home' packages,
- simultaneously attempt to reduce the numbers of patients eligible for CHC care funding.

This appears to be the intention of LLR CCGs which describe themselves as "*outliers in terms of cost and number of packages";* and describe their intention for "*robust application of guidance and scrutiny of package costs*" and "*review of high cost placements*". Both strategies would be hugely detrimental to *"…the most vulnerable and dependent people in our [LLR] society*".

SIA cautions against these measures, not least of all because there will be an inevitable 'knock-on' effect on an already beleaguered social care budget in LLR - individuals with complex care needs will still have those needs and if they cease to be found eligible for CHC funding or that funding is reduced there will be an inevitable 'budget shifting' to the social care budget and/or to other parts of the LLR NHS provision. There is furthermore considerable doubt as to the lawfulness of CHC eligibility decision making that would be required to reduce significantly the numbers of patients eligible for NHS CHC funding in LLR.

LLR CCGs assert that their expenditure on NHS continuing healthcare is *"…more than the majority of other areas across England*". SIA's own analysis demonstrates that average CHC package cost per individual is very much in line with the national average for all CCGs in England, however, and that the expenditure on CHC by LLR CCGs is a function of higher than average numbers of people deemed eligible for CHC funding of their care. In view of the fact that eligibility is only determined after an extremely rigorous assessment procedure and in accordance with a National Framework for CHC implementation, SIA considers that it is unlikely that there are

many, if any, of the "*most vulnerable and dependent people in our [LLR] society*", therefore, who have unwarranted CHC eligibility status.

Reduction in NHS CHC budgets will, without doubt, negatively impact the ability of SIA's members to achieve and/or retain eligibility for CHC and adequate 'care at home' packages. Reduced packages of care will result in regression of SCI people's rehabilitation and psychological adjustment to the traumatic acquisition of paralysis and increase their demands on a wide range of other NHS services. SIA is equally concerned regarding the fate of patients with newly-acquired paralysis due to SCI. Reducing CHC 'care at home' packages of care is completely at odds with the extensive and expensive NHS-funded rehabilitation that such patients undergo to equip them for a positive future, and is likely to result both in delayed discharge from specialist spinal cord injury centres and/or their placement in nursing home settings from which (research conducted at Loughborough University shows: *Int. J. Environ. Res. Public Health* **2015**, *12*(4), 4185-4202) return to live in their family home is very problematic and in which their health and well-being is severely damaged.

Cuts in CHC 'care at home' packages will also inevitably result in the reduction of health and care support for some of the "…*most vulnerable and dependent people*…" with other impairments in Leicestershire and Rutland. It is therefore unconscionable and potentially unsafe to reduce CHC-funded care packages for these vulnerable and dependent people - not least of all because 'cuts come with consequences', including to the wider NHS and social care economy. At a societal level and from a moral perspective, reducing SCI people's CHC 'care at home' packages, and those of other impairment groups, will inevitably have the effect of reducing their Independent Living, and threatens to undermine 30 years of hard-won progress in the area of Independent Living for disabled people. Cutting NHS CHC budgets targets the most vulnerable people, and is immoral.

Recommendation:

SIA recommends that there be a fundamental rethink of the proposals to drastically reduce NHS continuing healthcare spend by CCGs in LLR as outlined in the draft STP, and of its assumption of the adoption of the revised '*Settings of Care'* policy (viz. STP: concrete actions – "…revise, consult and implement new settings of care policy") - disturbingly before a formal decision had been taken on the latter!

SIA considers that the CCG's "Settings of Care" revised policy should not be adopted until the Sustainability and Transformation Plan for LLR is amended and consulted on.

Dr RT Earl
Hon. Lead on Care Policy
Spinal Injuries Association March 24, 2017