

Purpose:	Mamillan's response to the call for written evidence on the general principles of the Regulation & Inspection of Social Care (Wales) Bill
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1. Introduction

Macmillan Wales welcomes this opportunity to provide written evidence on the general principles of the Regulation & Inspection of Social Care (Wales) Bill. We believe that a change to the regulation and inspection regime is timely considering:

- The substantial and whole system change brought about through the Social Services & Wellbeing (Wales) Act and the need to ensure that implementation, consistently across the health and social care system is achieved.
- The nature of the incidents brought to the fore through respective enquiries in Wales & England reflecting negligence and poor care.
- The need to ensure that people are put in the driving seat of the services they receive, and that vitally, they have a key role to play in the regulation and inspection function in partnership with the respective bodies.

Although Macmillan services do not fall directly under the remit of the Bill, as an organisation working closely with people affected by cancer, we have a strong desire to ensure care and support services are able to provide the level of services potentially required by patients through their treatment and beyond. We have made the following general comments and suggestions on the Bill as it is currently drafted.

2. The Changing Story of Cancer

As the diagnosis and treatment of cancer is becoming ever more effective, many more people are living longer with and beyond cancer. There are currently 130,000 people are living with cancer in the Wales – a number set to double by 2030.

As the nature of cancer care and treatments changes, so do the needs of people who are affected by it – and the range of health and social care professionals and

services required to help meet those growing needs. This increase in the cancer population will have significant implications for both health and social care and will challenge existing models of cancer care. It is imperative that action is taken to ensure that care is holistic with non clinical needs routinely considered and covers social, financial, emotional, practical, psychological, spiritual and information needs. People need care beyond the clinical to enable them to live as well as possible and to become partners in their care enabling them to self manage as far as possible.

People who decades ago would have died shortly after diagnosis will increasingly survive for longer. 1 in 4 people will be living with the consequences and many will be living with an incurable cancer, remission and relapse. More focus is needed on this period of survivorship to improve quality of life, support patients to live well, as many more will be living with cancer, or the consequences of cancer as a long term condition.

3. Implications for Social Care in Wales

With instances of cancer diagnosis, and cancer survival both increasing it is vital that services are able to meet increasing demand for care and support. We know that, following treatment people affected by cancer can often face a cliff edge after their hospital treatment there is a lack of awareness about and uptake of services that are able to provide the care to help them maintain independence and positive progress. Publicised in 2013, produced in partnership between Macmillan and the Welsh Government, the Wales Cancer Experience Survey (CPES) provides a rich source of information relevant to this Bill. The CPES highlighted that there is overwhelming evidence that having a Clinical Nurse Specialist as a Key Worker enhances the delivery of cohesive care and provides an overall more positive experience for patients and their families throughout and beyond their treatment.

The CPES revealed that in a considerable amount of cases, patients were not able to access the care/help they required following treatment. Patients with a specialist cancer nurse, for example, as their key worker experienced a higher rate of access to additional services. But for those without, only 40% of patients were able to access the care/help they required. In addition the CPES revealed that older people, particularly those in the 75+ age group were far less likely to have received information about care/help available to them.

The regulation and inspection regime must and should take account of how effective the links between the health and social care workforce is. If needs are not met in a holistic way throughout an individual's cancer experience, we are concerned that this will result in increasing poor health, isolation and a reduction in wellbeing. It is disappointing therefore that the Bill only accounts for co-operation in relation to social workers. Joint working by regulatory bodies, should at its very minimum, encompass the NHS.

In its present drafting the Bill does not reflect a desirable person centred approach to the provision of care services. The Social Services & Wellbeing (Wales) Bill achieved a strong focus on preventative and person centred services, we believe that much of the narrative and language should be echoed in this Bill to ensure consistency.

With increasing financial and demand related challenges, we must continue to strive to look at innovative social care models that enhance care and support to meet increasing demand. We are keen to ensure that the Bill allows flexibility to capture these services in a way that maintains a desirable level of safeguarding along with ensuring the autonomy of services to develop in an innovative way. We welcome the provision for Local Authorities to hold an oversight of the social care market to ensure planning and service gaps are readily identified. We suggest that additional detail is require to properly highlight the role of the third sector and social enterprises in this respect, as has previously been done under functions in the Social Services & Wellbeing (Wales) Act. We feel that the knowledge, insight and expertise held within the third sector should be fully valued and recognised through provisions in the Bill.

4. Conclusion

Macmillan Cancer Support welcome the move toward re-shaping how regulation and inspection of social care operates in Wales. As a member of the Wales Carers Alliance and the Welsh Reablement Alliance we fully endorse and support the responses put forward by both respective alliances.

We hope you find the above narrative and information useful in shaping the next phase of the Bill process, if you would like any further information, or would like to discuss any of this response in more detail, please contact Matthew Kennedy (Policy Officer, Wales): [REDACTED]