the Responsibility Deal—eg, the need for robust, independent, transparent scrutiny of commitments made and the benefits of a local approach.

Public health sits within a wider socioeconomic system. The project was developed to operate at this scale by a public health team in the region that was prepared to take a risk with an unproven concept. Critics need to accept that insufficient evidence that an intervention is meeting planned commitments do not equal evidence that such initiatives do not work. The scepticism with which projects of this nature have been met suggests a partisan view made rather than objective evidence. A reconsideration of this stance is in order.

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Hydroxycarbamide use in young children with sickle-cell anaemia

The report by Winfred Wang and colleagues (May 14, p 1663) provides encouraging results from the safety studies of the use of hydroxycarb-amides in young children. However, the conclusion that these agents can now be used in all children with sickle-cell anaemia might be premature, since there are still several unanswered questions.

First, given the current knowledge about disease phenotypes, it is not clear that the sample size in this study captured a fair representation of severe disease phenotypes. Thus whether the safety profile of this drug will justify its use in all or a select group of young infants with sickle-cell anaemia remains an open question.

Second, and perhaps more important, is the need to address the potential use of this drug where it is likely to have the most effect on global health—ie, settings with a high prevalence of sickle-cell anaemia and poor health-care infrastructure. What is the potential effect of long-term neutropenia and hyposplenism on the outcome of patients in settings where malaria is endemic and invasive bacterial infections are highly prevalent? Will the hydroxycarbamides in these settings reduce the need for frequent blood transfusions where safe blood transfusion cannot be readily guaranteed? The genotoxic and teratogenic potentials of this drug require more data.

Now is also the appropriate time to initiate dialogue with the manufacturers of this drug, international donor agencies, and national governments in the sub-Saharan region to ensure easy access, once safety and efficacy is proven in that region.

We declare that we have no conflicts of interest.

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Need to realign patient-oriented and commercial and academic research

Clinical research is motivated by several factors. Some are more defensible than others, but most clinical researchers would state that their research is intended to improve health-care effectiveness and safety. There are examples where patients have succeeded in influencing what gets studied, but these are exceptions.

I have had the opportunity to consider from more than one perspective the mismatch between

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what clinical researchers do and what patients need. I am a researcher; I have responsibility for allocating funding for research; and I have had multiple myeloma for the past decade. A few years ago I stated publicly that several uncertainties I faced at the beginning of my disease were avoidable.1 Almost 10 years later—aft er a relapse of my disease—I looked at the “epidemiology” of myeloma studies on ClinicalTrials.gov. On July 31, 2011, a search using the term “multiple myeloma” identified 1384 studies. Of these, 107 were phase 2/3 comparative studies. However, in only 58 of these studies was overall survival an endpoint, and in only ten of these was it the primary endpoint. No trial was a head-to-head comparison of different drugs or strategies. Meanwhile, experts feel that cytogenetic studies and gene-expression profi ling will lead to personalised treatment in myeloma.2 and gene-expression profi ling will lead to personalised treatment in myeloma.3 Meanwhile, experts feel that cytogenetic studies and gene-expression profi ling will lead to personalised treatment in myeloma.4 and pharmaceutical companies to personalised treatment in myeloma.5 and gene-expression profi ling will lead to personalised treatment in myeloma.6 and gene-expression profi ling will lead to personalised treatment in myeloma.7 experts feel that cytogenetic studies and gene-expression profi ling will lead to personalised treatment in myeloma.8 and gene-expression profi ling will lead to personalised treatment in myeloma.9 Meanwhile, experts feel that cytogenetic studies and gene-expression profi ling will lead to personalised treatment in myeloma.10 and gene-expression profi ling will lead to personalised treatment in myeloma.11 Meanwhile, experts feel that cytogenetic studies and gene-expression profi ling will lead to personalised treatment in myeloma.12 and gene-expression profi ling will lead to personalised treatment in myeloma.13 Meanwhile, experts feel that cytogenetic studies and gene-expression profi ling will lead to personalised treatment in myeloma.14 and gene-expression profi ling will lead to personalised treatment in myeloma.15 Meanwhile, experts feel that cytogenetic studies and gene-expression profi ling will lead to personalised treatment in myeloma.16 and gene-expression profi ling will lead to personalised treatment in myeloma.17 Meanwhile, experts feel that cytogenetic studies and gene-expression profi ling will lead to personalised treatment in myeloma.18 and gene-expression profi ling will lead to personalised treatment in myeloma.19 Meanwhile, experts feel that cytogenetic studies and gene-expression profi ling will lead to personalised treatment in myeloma.20 and gene-expression profi ling will lead to personalised treatment in myeloma.

An essential component of any new governance strategy would be to bring together all the stakeholders, starting from an analysis of existing and ongoing research, produced independently of vested interests. Patient advocacy groups in myeloma spend millions to support research, hoping to promote better care. With public support they should be in a strong position to call for a redefinition of the research agenda, in the interests of patients. I hope this approach can be further debated in The Lancet for many other areas of clinical research in oncology and beyond.

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