

## Implications of the current UK welfare reforms for adults with cystic fibrosis

In common with other patients with chronic health conditions, adults with cystic fibrosis (CF) in the UK are eligible to claim for a variety of government-funded social security benefits. However, the UK government has recently announced planned changes to this system. In order to examine the potential implications of these reforms, a survey of 100 adults attending a regional CF centre was conducted. The majority of CF adults currently claim benefits and most are concerned by the planned reforms. Further work needs to be done to investigate the financial impact of the proposed welfare reforms on adults with CF before these changes are imposed.

## Background

Improvements in CF care have resulted in dramatic improvements in the life expectancy of people with CF.<sup>1</sup> As a result, the vast majority reach adulthood and need to consider entering into further education and/or paid employment. However, there are a number of potential barriers to adults with CF starting a career, including physical, educational and psychosocial factors.<sup>2–4</sup>

As their health deteriorates, the ability of CF adults to remain in education and employment declines. In common with other people with chronic health conditions, adults with CF in the UK are eligible to claim for a variety of government-funded social security benefits. Following the global financial crisis, the UK government announced changes to the way that the welfare system is administered. However, the implications of these reforms for adults with CF are not well appreciated. A questionnaire-based survey to determine the views of adults with CF was therefore conducted.

## Method

Adults with CF attending the outpatient clinic at the West Midlands Adult CF Centre in June and July 2011 were asked to complete a written survey questionnaire. The anonymous questionnaire asked for patients' age and gender, whether they were

in employment or studying, which benefits they were currently claiming and how concerned they were about the planned welfare reforms. Patients were also able to write specific concerns in a free-text section at the end of the questionnaire.

## Results

One hundred consecutive patients (55 male) completed the survey, with median age of 28 years (interquartile range (IQR) 21–34 years). Fifty-two patients were in full or part-time employment. Fourteen patients were not employed but were studying, either part time or full time. Three patients were employed and also studying part time. Thirty-four patients were neither employed nor studying and the median age of these patients was no different to those employed and/or studying (both groups 28 years). Significantly more females (23 patients) than males (13 patients) were neither employed nor studying ( $p < 0.005$ ). The survey did not collect data on childcare duties and it can therefore not be clarified as to whether this factor could explain the observed lower numbers of females in employment or studying.

Ninety-six patients reported that they received one or more benefit, with 91 receiving disability living allowance (DLA). Additional benefits received included incapacity benefit (21 patients), housing benefit (18 patients), council tax benefit (17 patients), income support (14 patients), tax credits (11 patients), council tax disability reduction (nine patients), severe disablement allowance (eight patients), employment and support allowance (five patients), and job seekers allowance (three patients). Patients who were neither employed nor studying received a significantly higher total number of benefits than those patients employed or studying (two benefits (IQR 2–4) versus one benefit (IQR 1–2),  $p < 0.0002$ ).

Patients were asked 'How concerned are you about the current welfare reforms?' with a scale between one (not concerned) and 10 (very concerned). Median score was 7 (interquartile range 5 to 8.25). There was no correlation between gender, age, employment or educational status and the level of concern. Free-text comments

included: 'my benefits enable me to work, which in turn helps me to stay well' and 'it is hugely stressful, I have lost sleep and my health has declined since being notified'.

## Conclusions

Despite suffering from a chronic life-limiting illness, the majority of CF adults are either studying or in employment. Almost all patients currently claim benefits and most are concerned about the implications of the current welfare reforms. Further work needs to be done to investigate the financial impact of the proposed welfare reforms on adults with CF before these changes are imposed. In particular, since adults with CF incur significant personal expenses in relation to their CF-specific care (including prescription charges, hospital car parking fees and travel expenses to clinic appointments), the potential health implications of the proposed reforms are a concern.

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## References

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