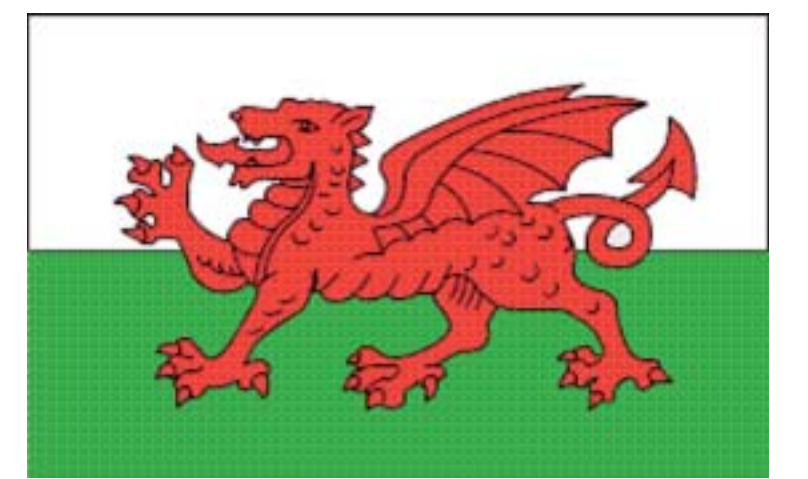


# The Views of Adolescent Cystic Fibrosis Patients

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## Introduction

Adolescence has been described as a complex stage of development. During this phase the young person is attempting to come to terms with a changing physical appearance, acquire a sense of identity, independence and vocational/academic achievement <sup>1</sup>. For the adolescent who suffers from cystic fibrosis (CF) the stage is fraught with further difficulties to overcome. The young person has to also juggle their health needs and develop a sense of independence in their care in preparation for the transition to adult services.

## Method

An anonymous questionnaire was distributed to 15 adolescents with cystic fibrosis aged 10 years or over in December 2002.

## Aims

Ascertain the views of adolescents in relation to the CF service provided.

To identify the views of adolescents in reducing the effect of CF and treatment on the adolescent's schoolwork.

To improve the transition to adult services.

## Results

Of the 15 questionnaires distributed 11 were returned 73% did not want to be seen by the CF team without their parents (figure 1)

64 % did not want a joint clinic with the adult team prior to transfer

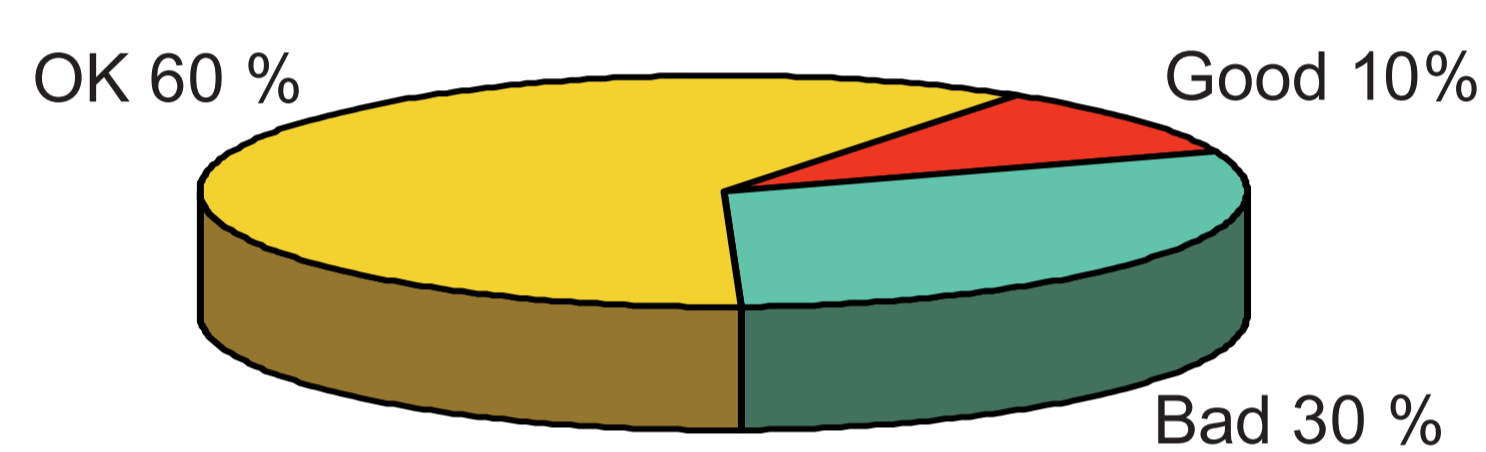
64% preferred an after school clinic (figure 2)

50% were prepared to undertake schoolwork whilst in hospital

30% thought the food inadequate on the ward (figure 3)

18% thought written information given regarding CF was inadequate (figure 4)

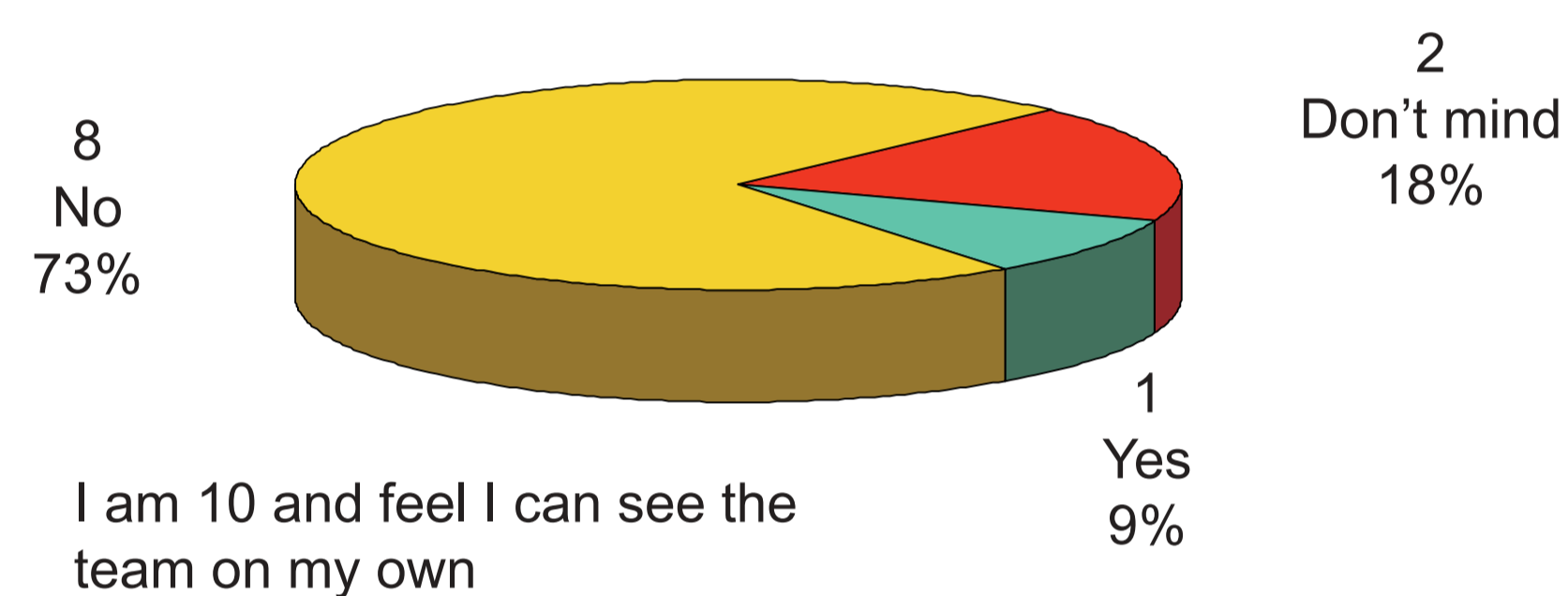
### What did you think of the food on the ward?



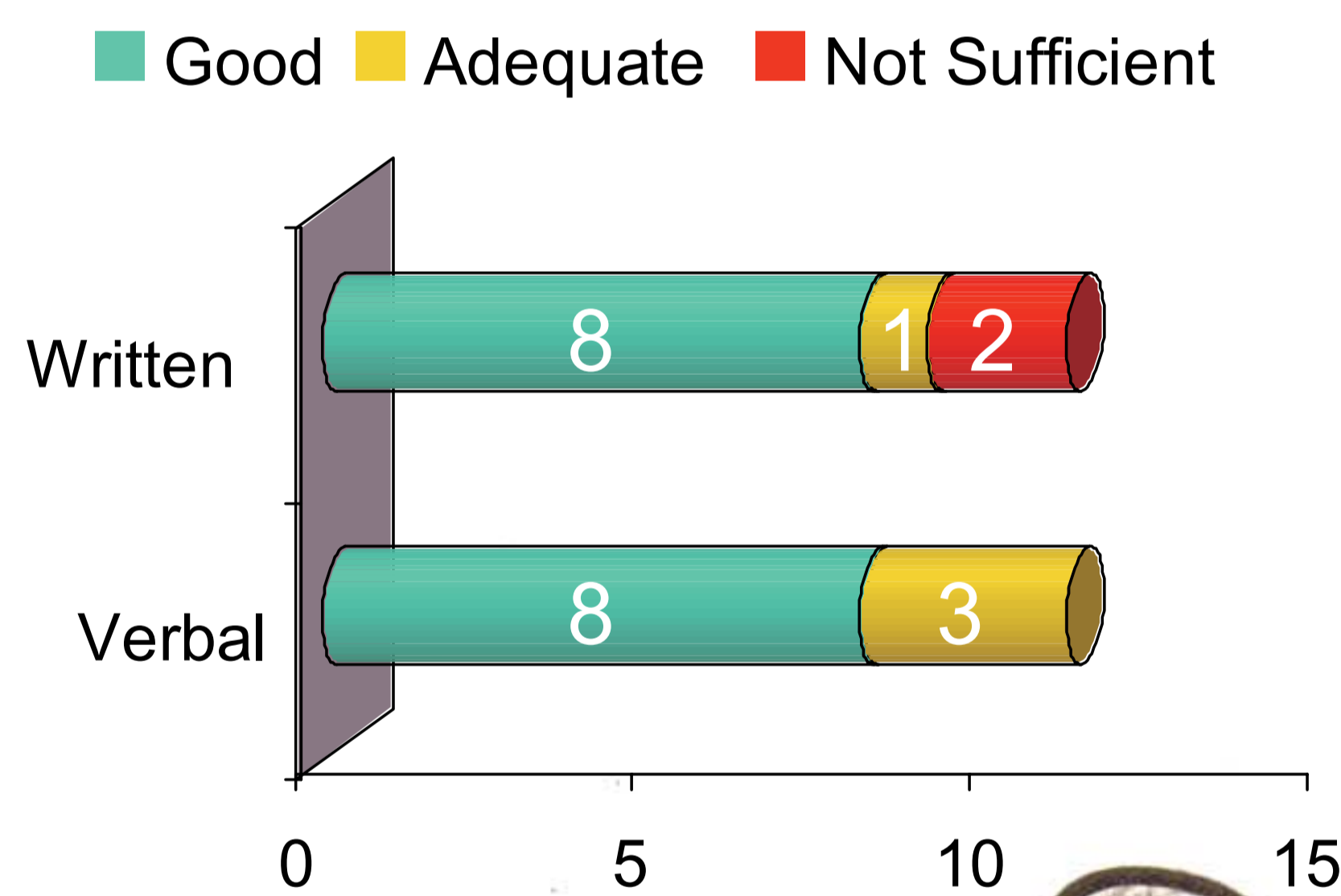
#### Comments

Chips and waffles soggy, try frying them.  
Make it smell, taste and look nice

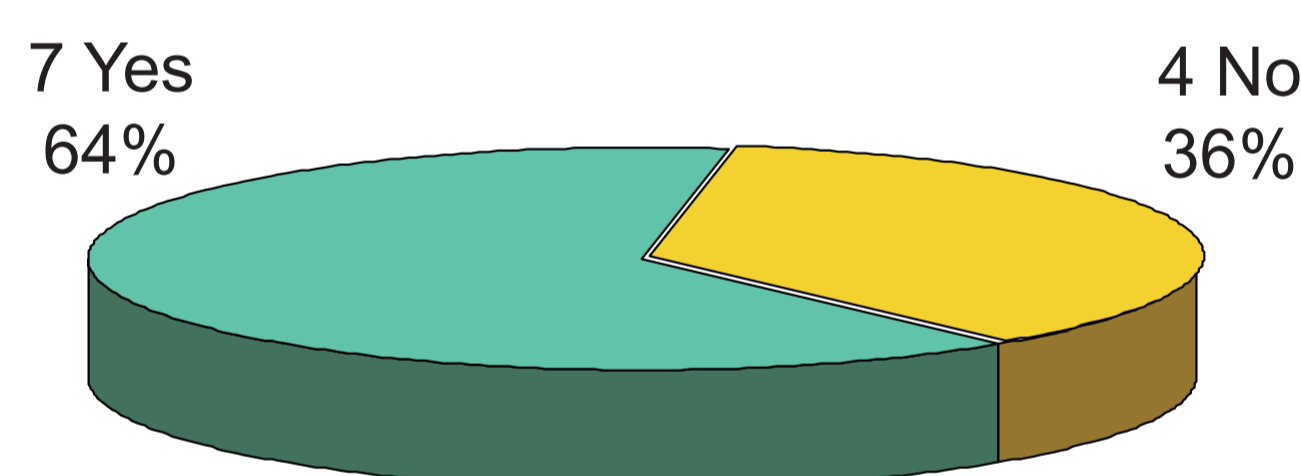
### Would you like to see the CF team without your parents?



### What do you think about the information provided in the clinic? (figure 4)

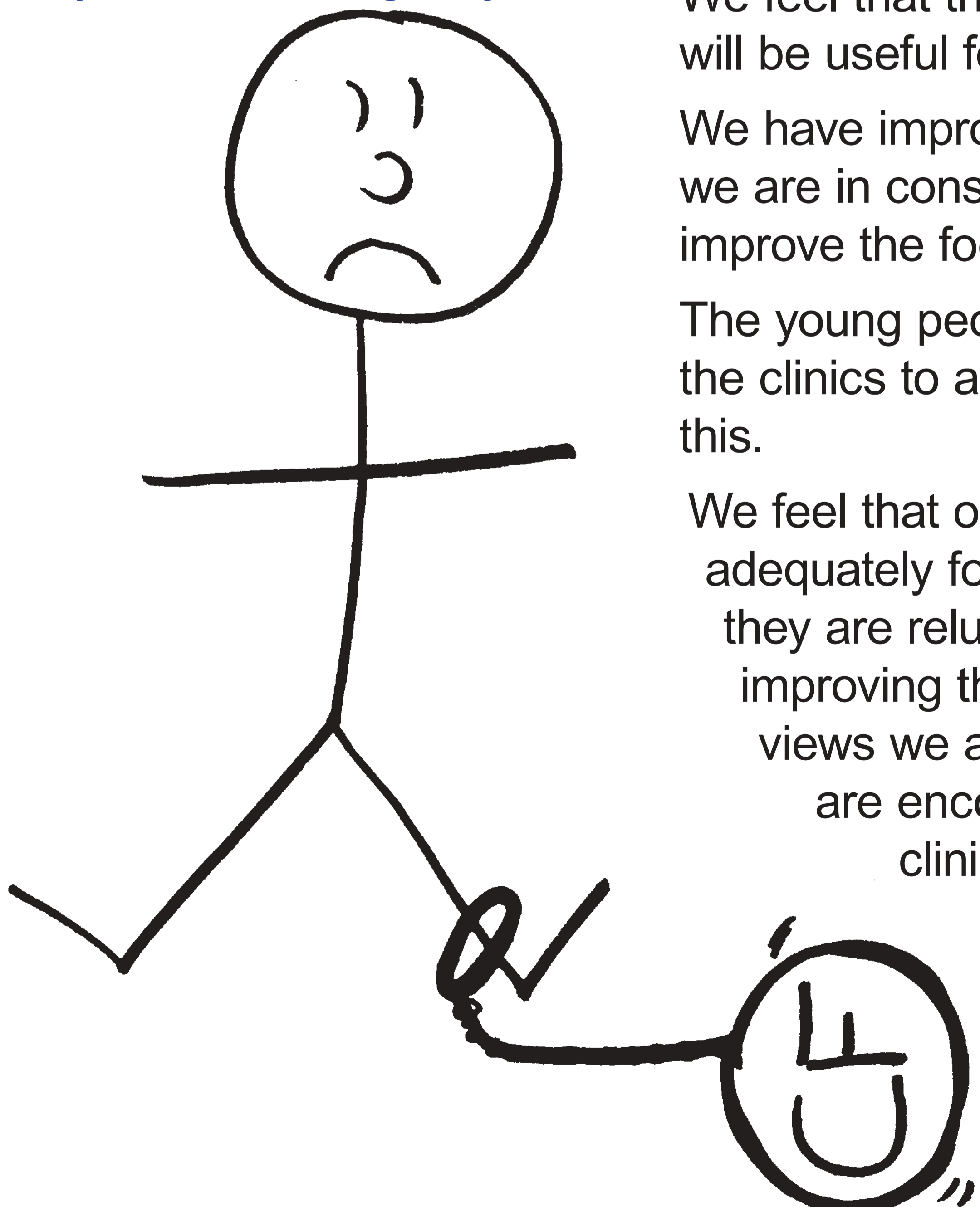


### Would you prefer to come to the clinic after school/college?



## What is Cystic Fibrosis !

by Nichola Heard age 18 yrs



## Conclusions

We feel that the views of our adolescent CF patients will be useful for us to further develop our services.

We have improved access to written information and we are in consultation with the hospital services to improve the food.

The young people were keen to change the times of the clinics to after school clinics and we plan to do this.

We feel that our adolescents are not being prepared adequately for their transition to adult services but they are reluctant to try new and differing ways of improving the transition. Despite their negative views we are planning transitional clinics and we are encouraging them to undertake part of the clinic consultation process with various paediatric CF team members without their parents.



## Reference

<sup>1</sup> Muller D.J., Harris. P, Watley L, Taylor J (1992) Nursing Children Psychology, Research + Practice, Chapman Hall, London.