



Children & Young People's Allergy
Network Scotland



Young People's views on allergy services in Scotland Evaluation Report 2013



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Introduction

CYANS conducted a survey in collaboration with Young Scot to find out young people's views, (aged 11 - 19), on their allergy care and needs for future allergy care. The information has been used by CYANS to identify gaps or areas of allergy care that require change and it has informed recommendations for improvements in future allergy care provision, including developing a pathway of care into adult services for young people.

The respondents

The survey received a total of 139 respondents; responses were received from the majority of local education authorities' areas (*table 1*). The majority of respondents were in the 11-14 year old category (56%) with 15-19 year olds making up approximately, 44% of respondents. Female respondents totalled 58% (79 / 139) and male 41% (58/ 139) with 1% (2/ 139) preferring not to say.

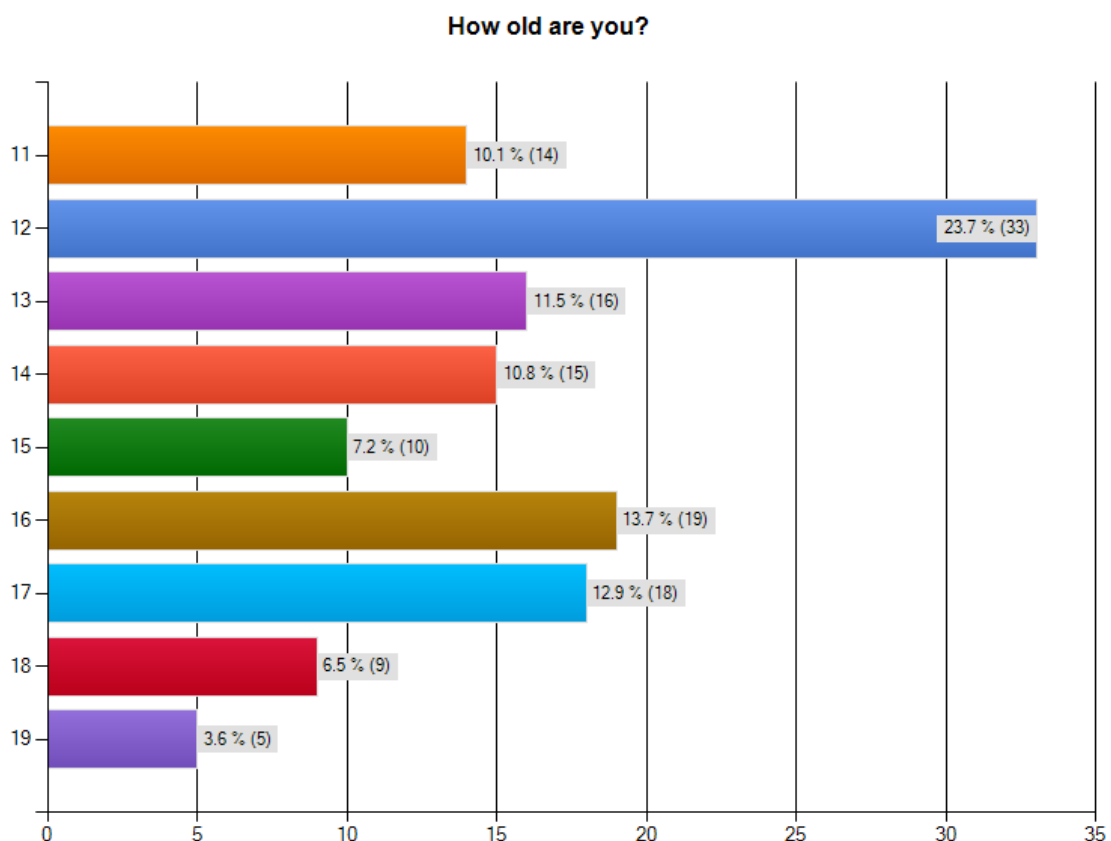


Table 1

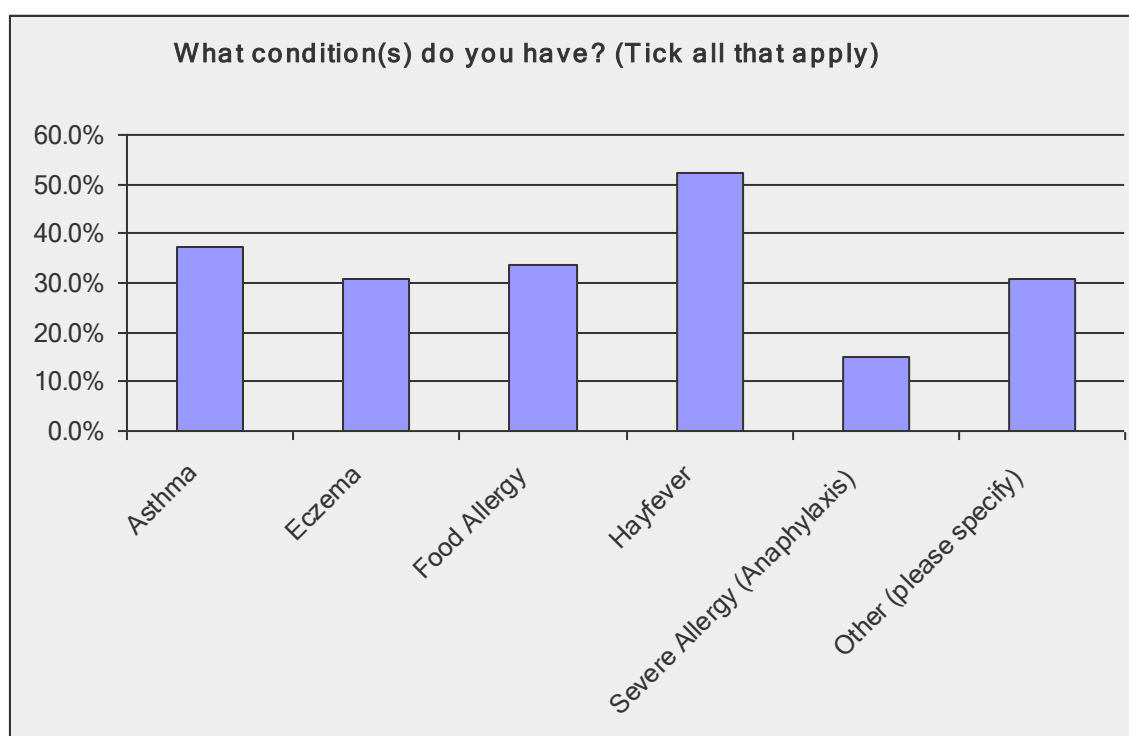
Local Health Authority	% of respondents	Total out of 139 respondents
Aberdeen City	2.9%	4
Aberdeenshire	3.6%	5
Angus	2.9%	4
Argyll & Bute	2.2%	3
City of Edinburgh	7.2%	10
Clackmannanshire	0	0
Comhairle nan Eilean Siar	0	0
Dumfries & Galloway	2.2%	3
Dundee City	3.6%	5
East Ayrshire	1.4%	2
East Dunbartonshire	2.2%	3
East Lothian	5.8%	8
East Renfrewshire	1.4%	2
Falkirk	2.9%	4
Fife	8.6%	12
Glasgow	9.4%	13
Highland	5.0%	7
Inverclyde	2.9%	4
Midlothian	2.2%	3
Moray	1.4%	2
North Ayrshire	1.4%	2
North Lanarkshire	5.8%	8
Orkney Islands	0	0
Perth & Kinross	3.6%	5
Renfrewshire	2.2%	3
Scottish Borders	1.4%	2
Shetland Islands	0.7%	1
South Ayrshire	3.6%	5
South Lanarkshire	2.2%	3
Stirling	1.4%	2
West Dunbartonshire	1.4%	2
West Lothian	8.6%	12

The Survey

The following questions were designed to collect information on young people's views about what allergic conditions they have how often they access health care for allergic conditions and what health care professionals they visit.

Allergic conditions of respondents

Participants were asked what allergic conditions they suffer from. The majority of respondents had hayfever 52% (73 / 139), followed by asthma 37% (52 / 139), food allergies 33.8% (47 / 139), eczema 30.9% (43 / 139) and severe anaphylaxis 15% (21 / 139). 'Other conditions' accounted for 30.9% (43 / 139) including allergies to drugs, grass pollen and animals. In addition hypersensitivity to irritants, e.g. soap and detergents, were mentioned, as well as other paediatric conditions not relating to allergy.



Health care usage

Participants were asked how often and which clinicians they see for their allergies and how involved they feel in the consultation and the management of their condition.

The response to 'how often do you visit a health care professional about your allergies' varied between every six weeks to once every two years.

The Respondents who indicated they see a healthcare professional for their allergy care once a month, all indicated they had asthma and were all being cared for by their GP.

Most of the respondents who indicated they never visit a health care professional for their allergies had hay fever (59%), 14% had food allergy and 2% multiple allergic

conditions. If they did need to see a healthcare professional they indicated they would see their GP.

None of those who indicated they never see a health care professional for their allergy had been prescribed adrenaline auto-injectors

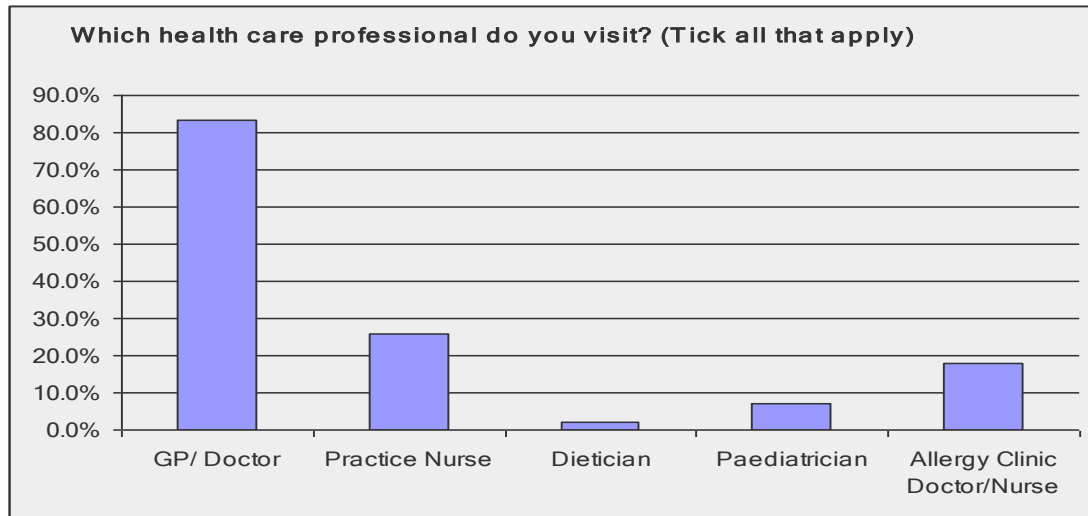
Other responses included;

- 'Varies due to conditions'
- 'Rarely do unless I take a reaction'
- 'Visit twice a year and in-between when I have flare ups '
- 'When my allergies get bad'
- 'When I need to '
- 'As and when required'

These responses suggest a need for a flexible approach to allergy care for young people.



When asked which health care professional they see for their allergies, the majority of respondents stated that they visit a GP (83.2%) or practice nurse (25.7%). Some also see specialist allergy services including allergy clinics (17.8%), a paediatrician (6.9%) and a dietician (2%).

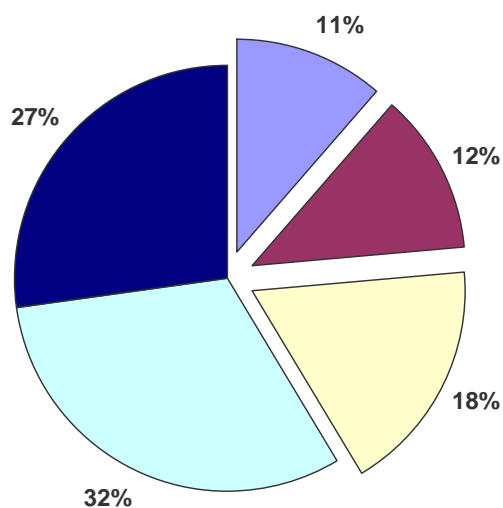


Involvement in consultations and management decisions

The survey contained the following questions to collect information on how involved young people felt in the consultation process for their allergy care and treatment.

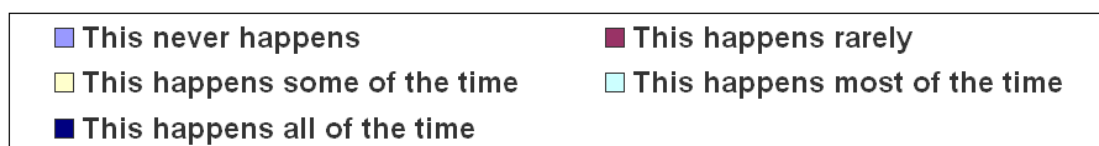
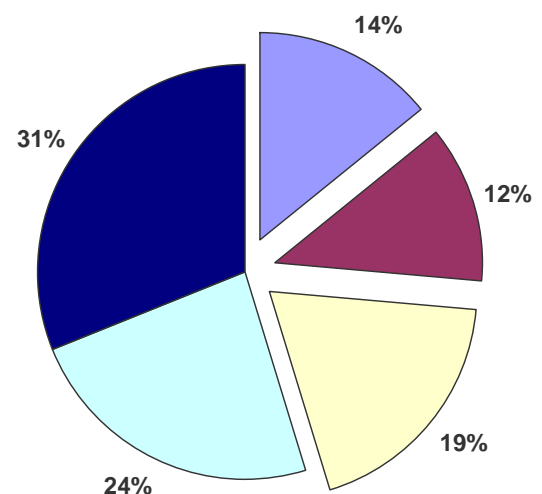
Graph 1

**Speak to me directly
(instead of my parent/carer)**



Graph2

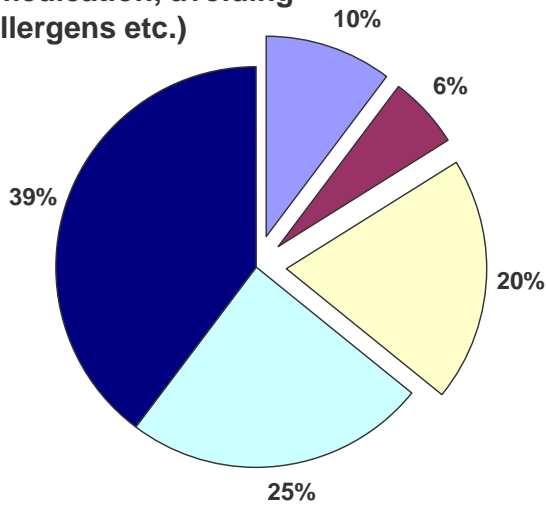
**Explain clearly what tests they need
to carry out and why**



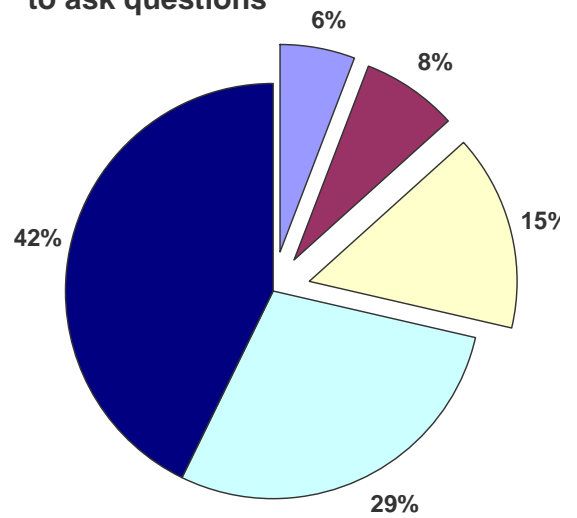
Graph 3

Graph 4

Explain clearly what I need to do to manage my allergy and why (medication, avoiding allergens etc.)

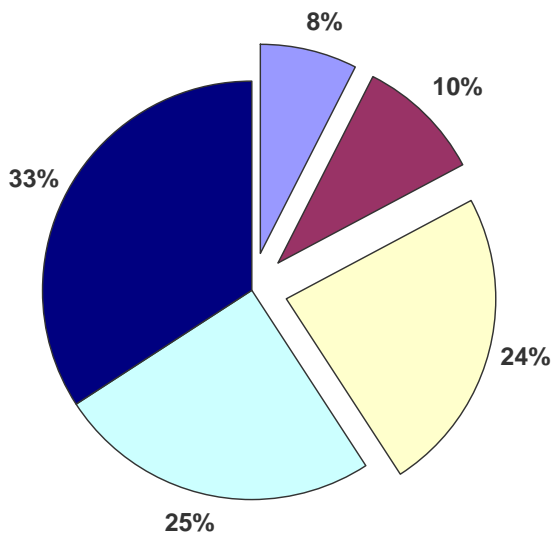


Give me an opportunity to ask questions



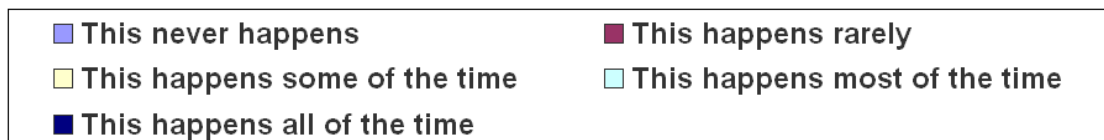
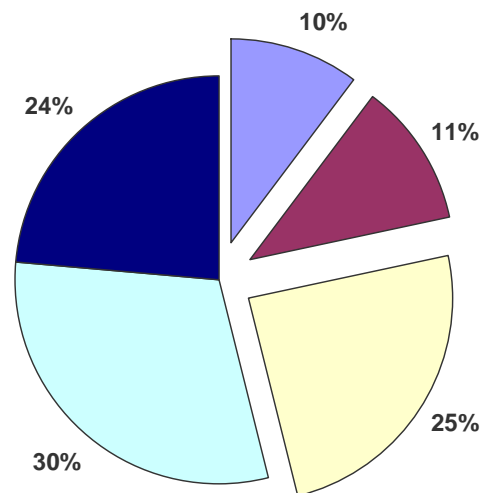
Graph 5

Listen to my worries and concerns



Graph 6

Involve me when making decisions about my health care



The results indicate that reassuringly between 55-70% of respondents to the survey felt that they were involved within the decision making process and their needs were being met by their current health care professional, however between 30-40% of

respondents felt that they were not directly involved in the consultation process and their needs were not being met.

Opinions on allergy care

The following questions were designed to find out what young people feel works within their current allergy care and what could be improved for future allergy care. (All the responses to these questions were free text answers)

What do you think is good about your allergy care?

The majority of responses for good allergy care related to;

Having access to the correct medication to control their allergies,

'There is medication to control my allergies', 'getting my medication is no problem', 'it keeps it under control', 'I'm given the right medication I need', 'appropriate medication'

Being involved in the decision making process about their care,

'Own opinion is asked regularly and I get the best help possible', 'they listen to my point of view', 'I always know what's going on', 'things are explained to me', 'I am actively involved'.

Health care professionals who listen

'Always there to talk to if I need it', 'take time to appreciate my concerns', 'not forced to do allergy test I don't want to',

Health care professionals who are friendly

'The doctors and nurses are friendly and welcoming', 'very supportive and nice'.

Feeling supported

'I think that the care I receive is very helpful as it helps me manage and keep track of my allergies. It provides me with the help I need in order to handle my allergies in the best way'

How do you think your allergy care and support could be improved?

Responses to this question included;

Wanting more regular visits to a health care professional with a specific interest in allergy

'maybe have annual visits to a dietician or food allergy specialist', 'regular appointments with allergy nurse', 'more regular visits to allergy clinic'

Wanting more choice / options to treat allergies

Medication

'my treatment has remained the same all my life and there must be more options to treat my condition', 'to have more choice in medication and more say', 'other alternatives to my treatment', 'they give me tablets for it and say there is nothing more they can do'

Information

'I would like to know more about my condition', 'more subject knowledge', 'talk about stuff that might happen'.

Provision of adult service

'Provide an adult service as when I turned 18 I was left high and dry without full support'

Being more involved in treatment

'Involve me in discussions', 'listen to my worries and try to help me more and support they are supposed to care',

Allergy care to be delivered more locally and in a timely manner

'More care in Highlands instead of having to go to Yorkhill (Glasgow)
'Being able to get an appointment more easily', 'treated quickly', 'more time available with GP, sometimes you can be rushed if GP is busy'

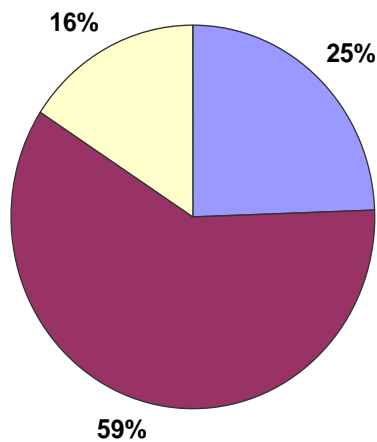
Awareness on the impact of living with allergy

'Increased public awareness', 'for more people to understand', 'more people should know what it is like and how it feels (to live with an allergy)',

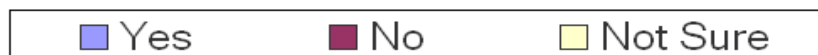
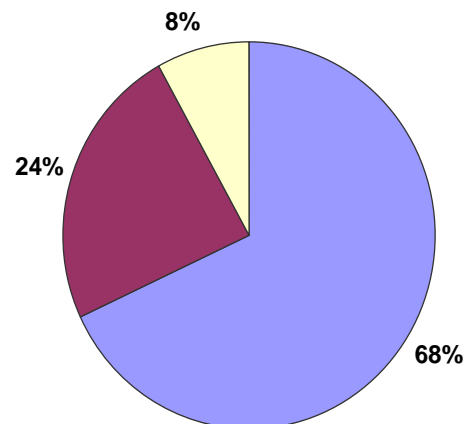
Management of severe allergies

The following questions were included in the survey to find out if participants with life threatening allergies are trained and confident in the use of adrenaline auto-injectors as emergency treatment.

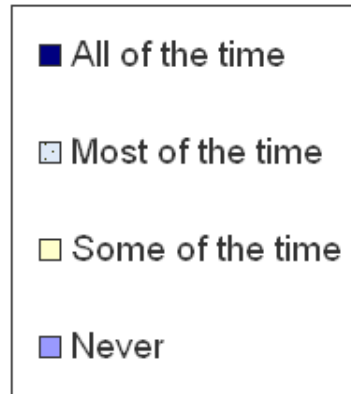
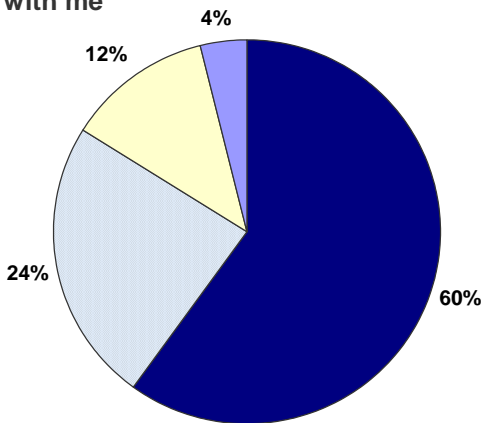
Have you been prescribed adrenaline (Epipen, Anapen, Jext) for a severe allergic reaction?



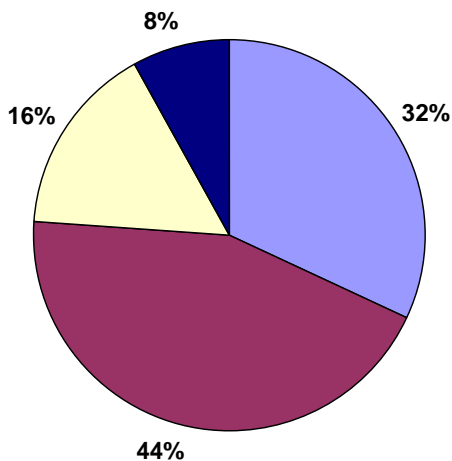
Have you been given training on how and when to use the adrenaline you have been prescribed?



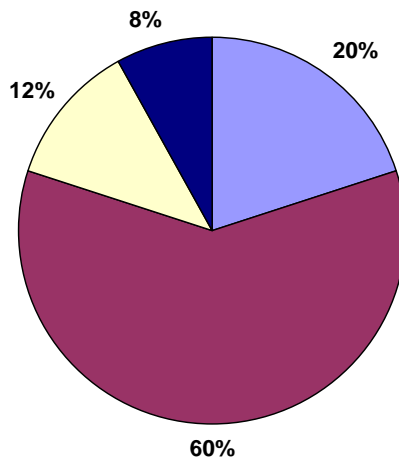
**I carry my rescue medication
(Epipen, Anapen, Jext, inhaler)
with me**



**I feel confident to use my
adrenaline in an emergency**



**I feel confident that staff at my
school would know what to do
in a anaphylaxis emergency**



Results

Of the 25 respondents who were aware they had been prescribed adrenaline auto injectors, 68% had received training, reassuringly 60% of respondents always carry their adrenaline auto injectors with them and 76% would feel confident to use their adrenaline in an emergency. However a worrying proportion of respondents indicated they had not received any training or were unsure if they had been trained to use their device (32%). 40% stated they don't always carry their adrenaline auto injectors,

including 16% who stated that they carry their adrenalin auto injector with them only sometimes or never. 24% indicated that they would not feel confident to use their adrenaline in an emergency.

It was reassuring to find that the majority of respondents (80%) felt confident that staff at school would know what to do in an allergic emergency; however 20% of respondents felt that staff in their school would not know what to do in an allergic emergency.

These results demonstrate the need for improved advice and support to educate and empower young people with life threatening allergies to develop more effective self-management skills. They also suggest a requirement for improved education and awareness for school staff to provide support to pupils with allergies.

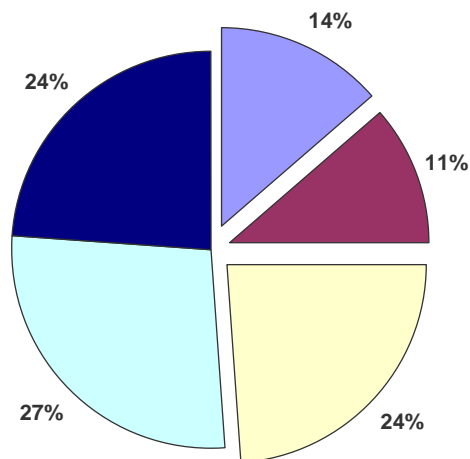
The impact of allergy on daily living

The impact of allergy on education

Young people were asked to respond to the following question;

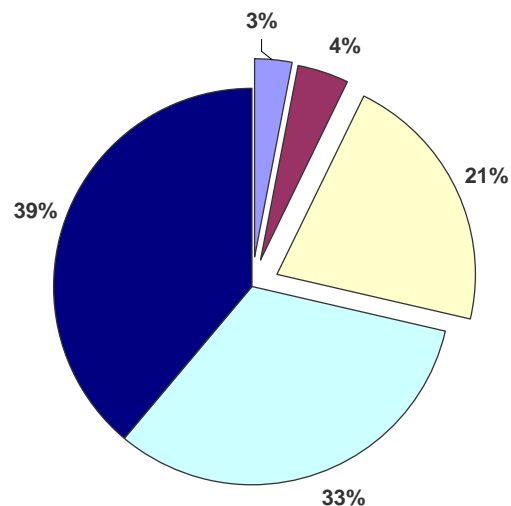
If you are at school or college, how does having an allergy affect your experience in relation to the following statements?

My allergy has little or no effect on my experience of school or college

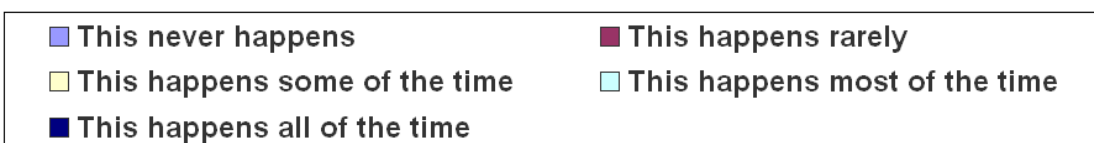


Graph 1

I cope well with my allergies at school or college



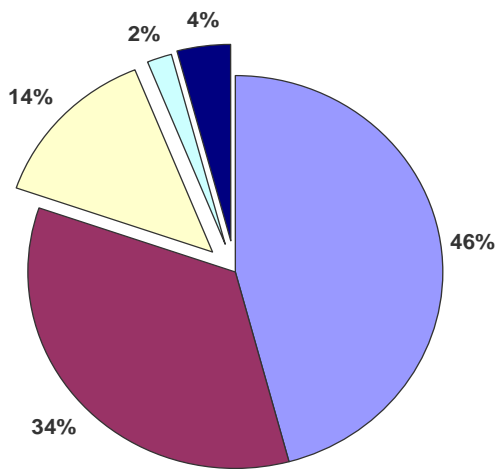
Graph 2



Graph 3

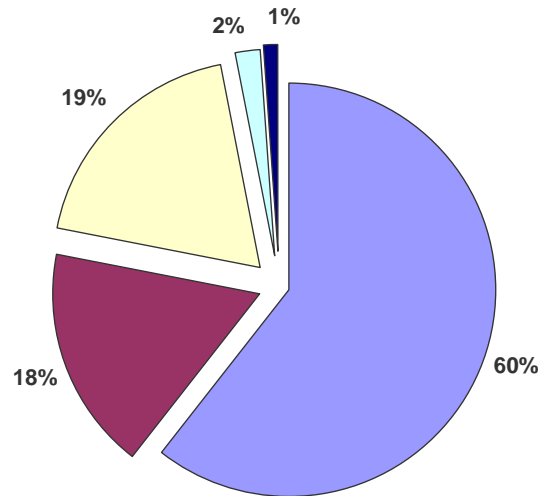
Graph 4

I miss classes due to appointments for allergy or illness



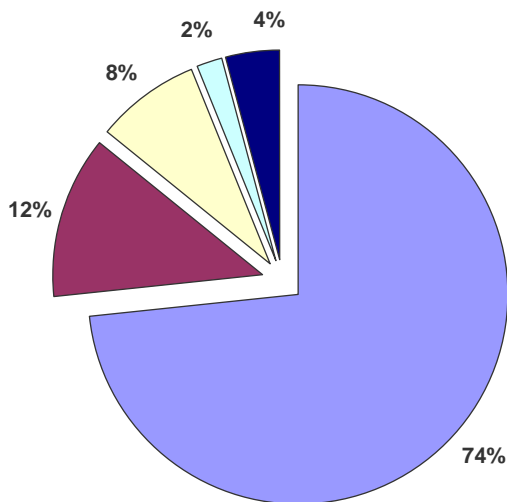
Graph 5

I can't do certain classes because of my allergies

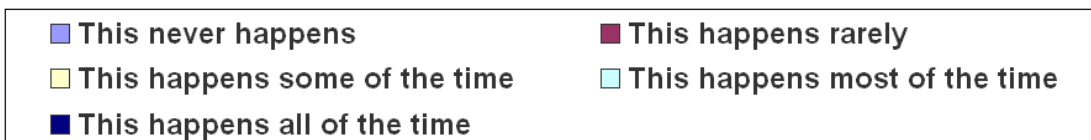
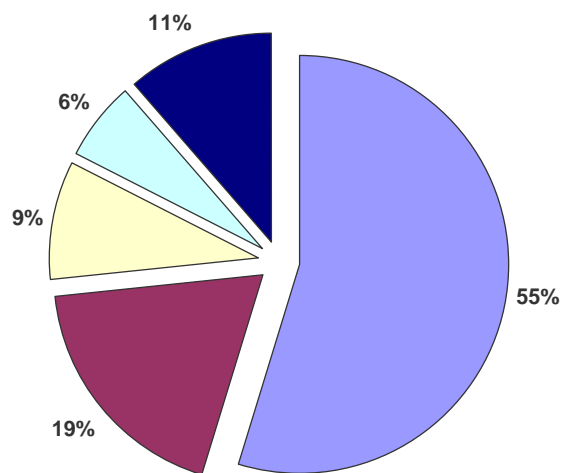


Graph 6

I experience bullying because of my allergies at school or college



I am limited in what I can eat from the canteen at school or college



Results

The results indicate that having an allergy does not impact on the overall experience of school or college for just over half (51%) of the respondents, reassuringly 72% feel they cope well with their allergies, the majority 80% feel that they don't miss classes due to their allergies, 78% felt they can participate fully in classes. 74% stated they have never been bullied as a result of their allergies and 55% report they have no problems eating from the school / college canteen.

However there are approx 20-30% of respondents who have highlighted regular problems with their allergies, with 25% stating having allergies affected their experience of school / college, 28% felt they don't cope well with their allergies, 20% who feel they miss classes as a result of their allergies and 22% who feel they are not able to participate fully in classes. A worrying 26% have experienced bullying at some time due to their allergies with 6% stating this happens most of the time, and nearly half of the respondents 45% have experienced problems and felt they are limited in the choice of food from the school or college canteen because of their allergies.

Provision of support to pupils with allergies in school or college

Participants were asked how support for young people with allergies could be improved at schools/colleges.

The majority of respondents would like better education for pupils 79% (74) and staff 73% (69) about what to do in an allergic emergency. Also identified as a high priority was the need for increased awareness and education amongst pupils 75% (70) and staff 71% (67) about what it is like to live with an allergy. Other suggestions included improved food labelling in the canteen 60% (56) and the provision of more allergy friendly options in the canteen 49% (46).

Further comments included;

'Make all staff aware of pupils with allergies and what their allergen triggers are'

"I Think The Staff Should Know What Allergies And Stuff You Have Because I Was Having An Asthma Attack Due To A Pollen Trigger Outside In PE And My Teacher Didn't Know. I Was In Hospital For 2 Weeks Afterwards :-("

'Canteen staff needs to be more aware, especially of cross contamination (food allergy)'

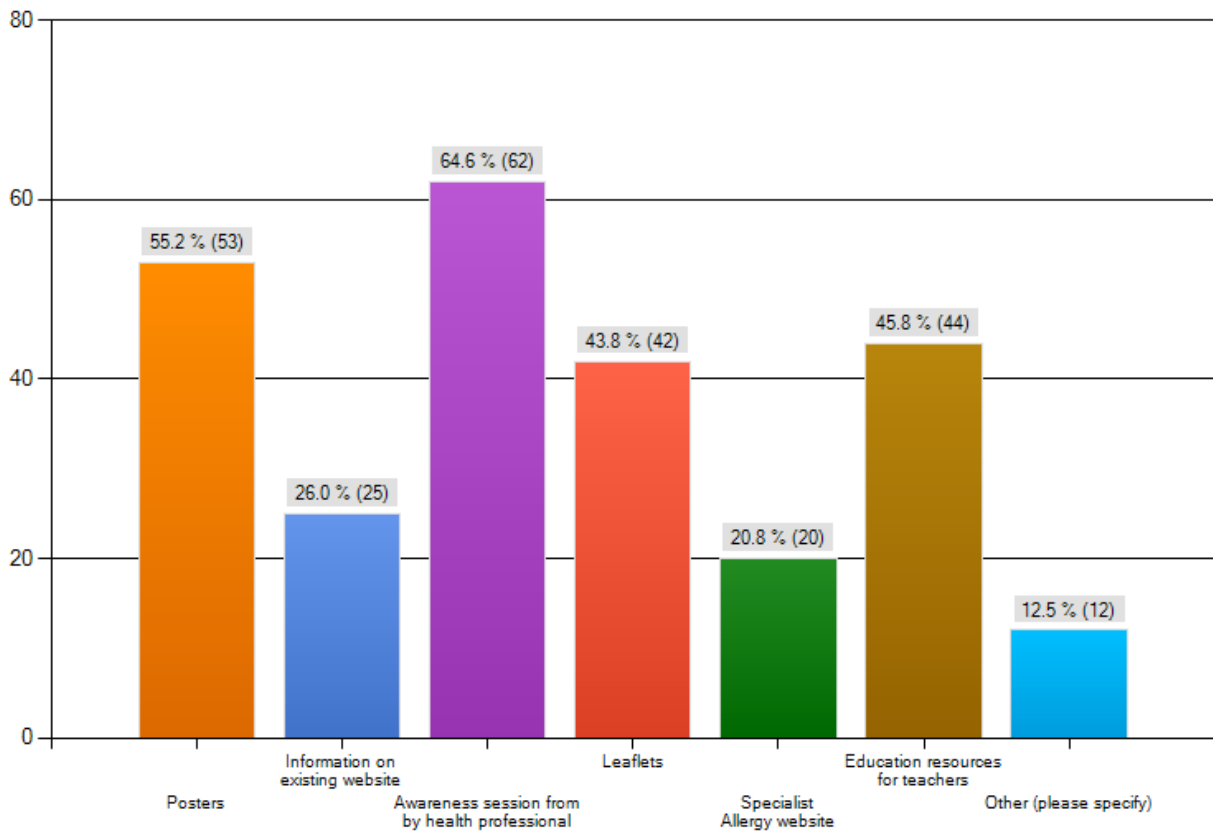
Asked how increased allergy information should be provided the majority of respondents (64.6%) favoured awareness sessions by health care professionals for the delivery of allergy information to staff and pupils in schools. The use of posters (55.2%), education resources for teachers (45.8%) and leaflets (43.8%) were also rated highly.

Other ideas included;

Talks or session from someone living with allergies

Interactive session for pupils to act out allergy situations – ‘everyone can be involved to help take in information’.

What do you think are the best ways to deliver information to staff and pupils? (tick as many as you like)



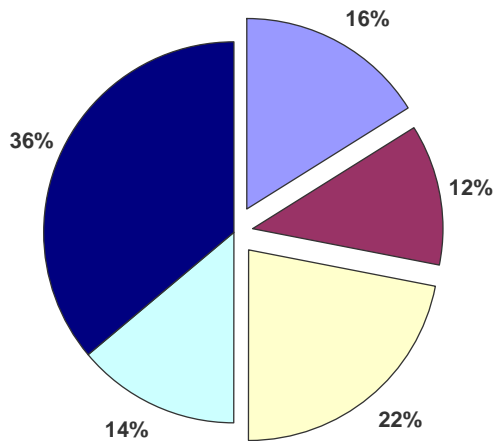
The Impact of allergy on work

Young people were asked to respond to the following statements related to the question;

If you work, how does having an allergy affect your work life?

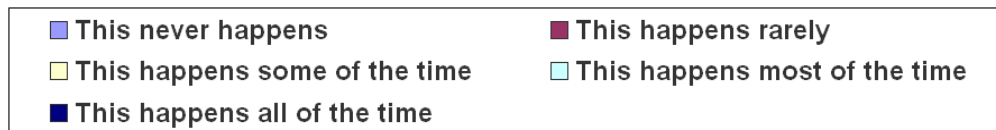
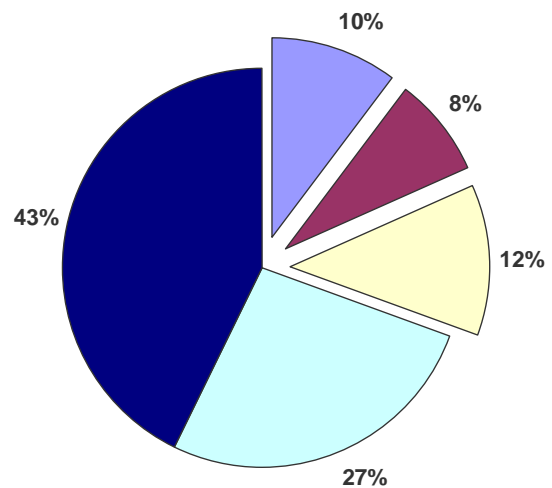
Graph 1

My allergies have little or not effect on my work life



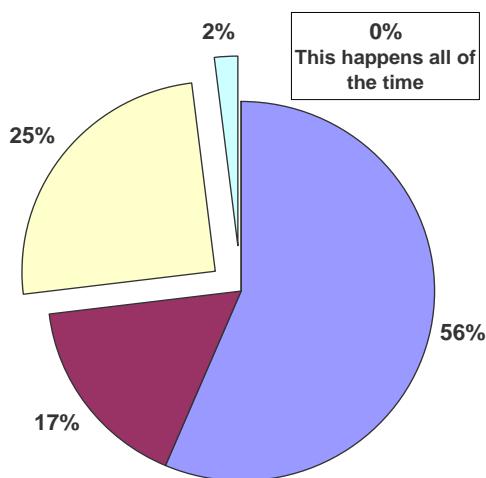
Graph 2

I cope well with my allergies at work



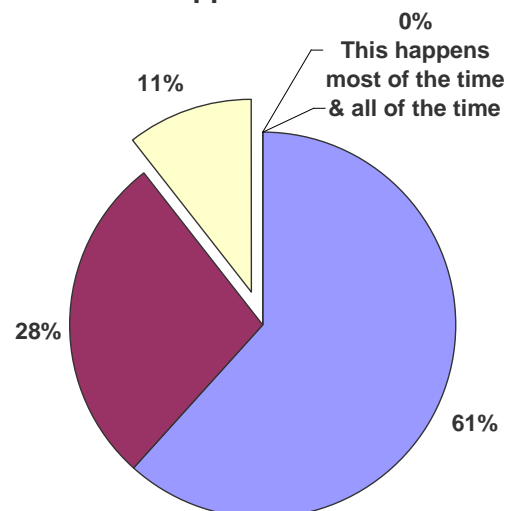
Graph 3

My performance at work is affected by my allergy



Graph 4

I have to miss work due to illness or appointments



Results

The results indicate that for half the respondent's allergy has little effect on their work life, with 70% feeling they cope with their allergies most of the time, and 73% feeling their performance is not usually affected by their allergies, 61% stated they do not miss work due to illness or appointments. However about half the respondents felt their allergies do have an impact on their work life with 30% feeling that they do not always cope well with their allergies, 27% felt their performance at work is affected to some degree by their allergies and 11% felt they needed to miss work due to illness or appointments related to their allergies

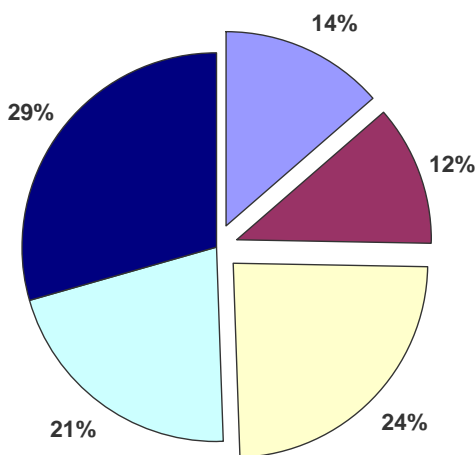
Impact of allergy on my social life

Young people were asked to respond to the following statements related to the question;

How does having an allergy affect your social life?

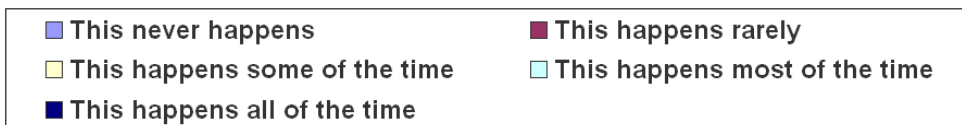
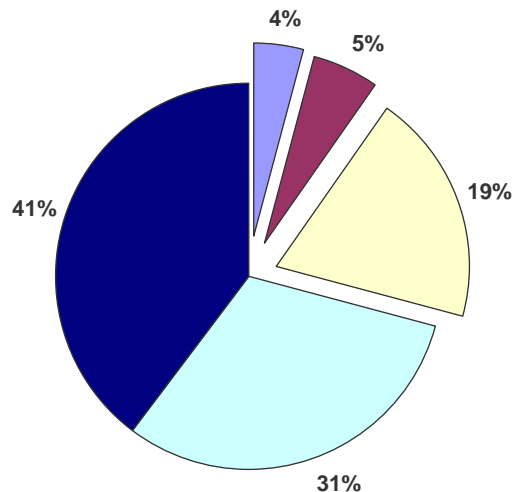
Graph 1

My allergies have little or no effect on my social life



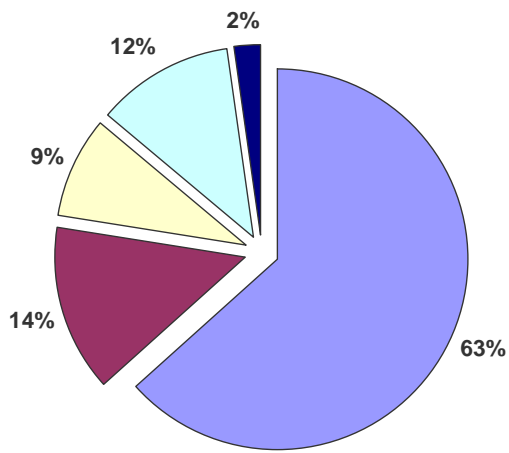
Graph 2

I cope well with my allergies socially



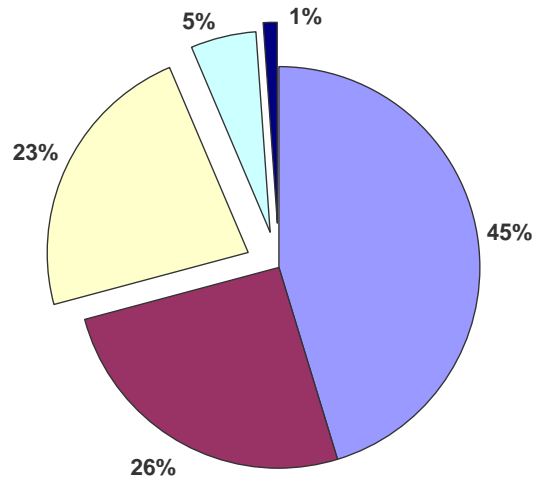
Graph 3

Having an allergy stops me eating out with friends



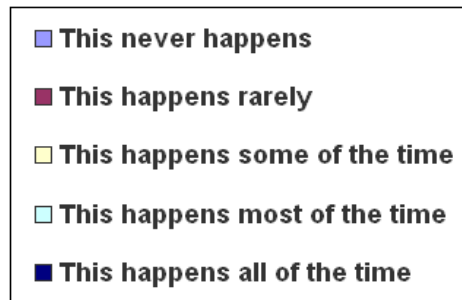
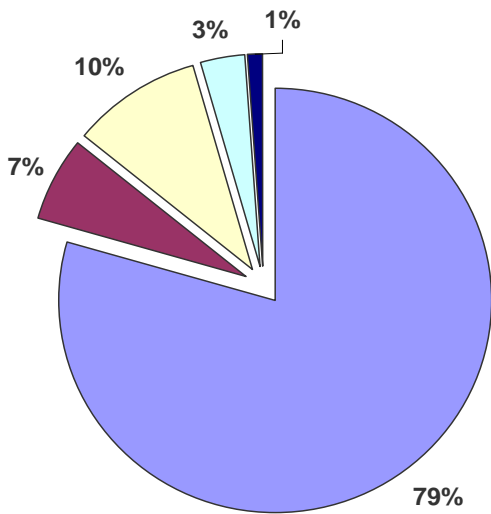
Graph 4

It stops me joining in activities with friends



Graph 5

I find it hard to make friends because of my allergy



Results

Half of the respondents to the survey felt that having an allergy did impact on their social life, with 28% who felt that they don't always cope well with their allergies, and 29% who felt that having allergies can stop them joining in activities with friends, including 37% who felt that having an allergy had stopped them eating out with friends and 14% who felt that having an allergy made it more difficult to make friends.

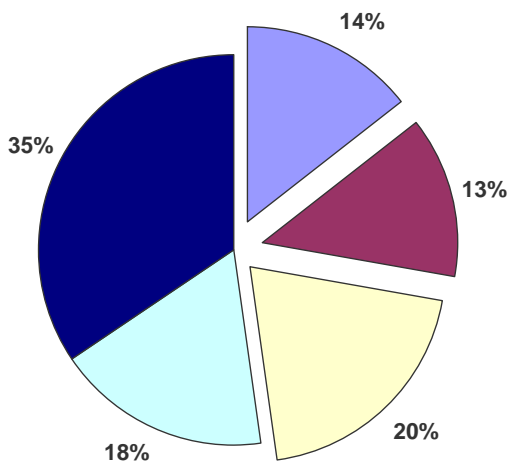
Living with allergy - How does it make me feel...

Young people were asked to respond to the following statements related to the question;

Living with allergy makes me feel?

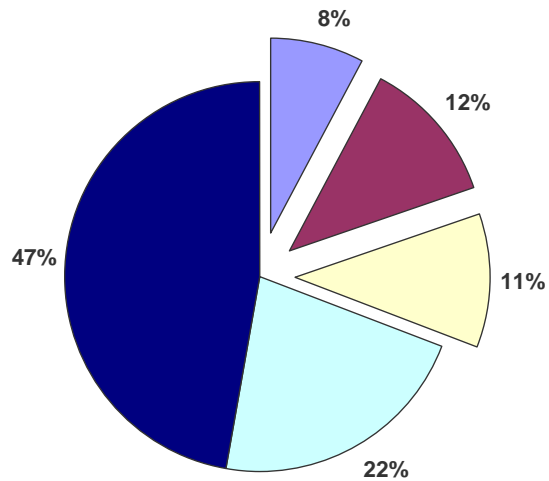
Graph 1

I feel proud/I cope well



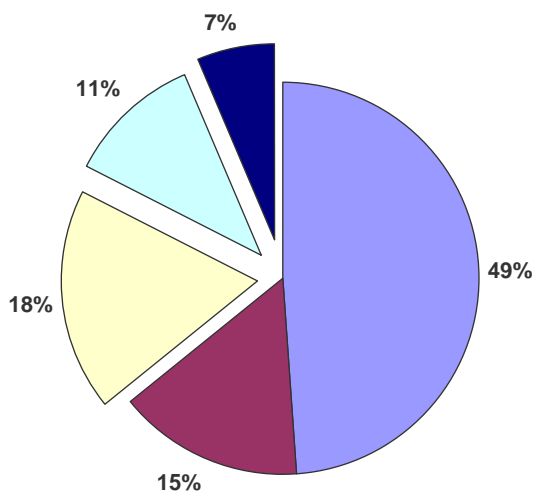
Graph 2

I feel supported (family & friends)



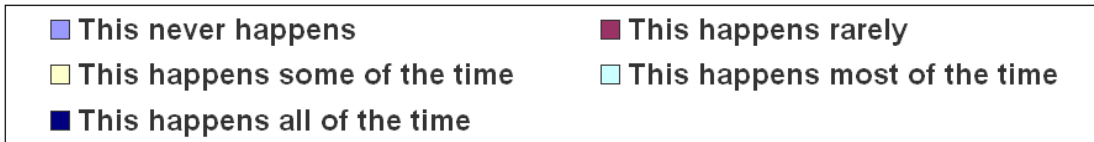
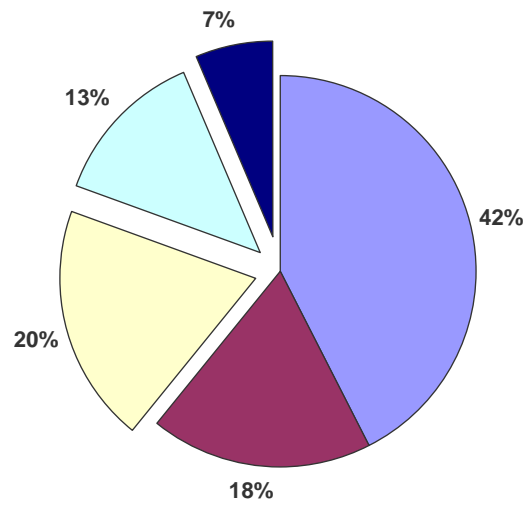
Graph 3

I feel embarrassed



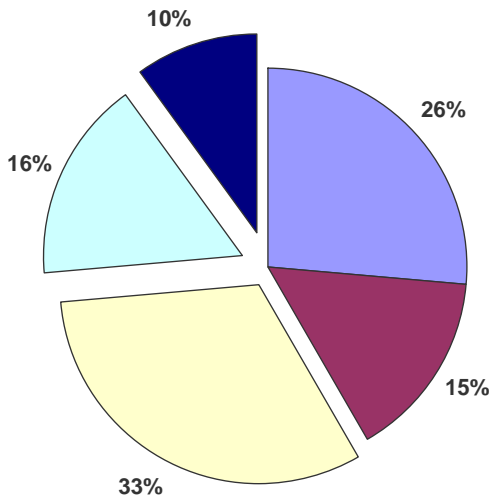
Graph 4

I feel anxious/stressed



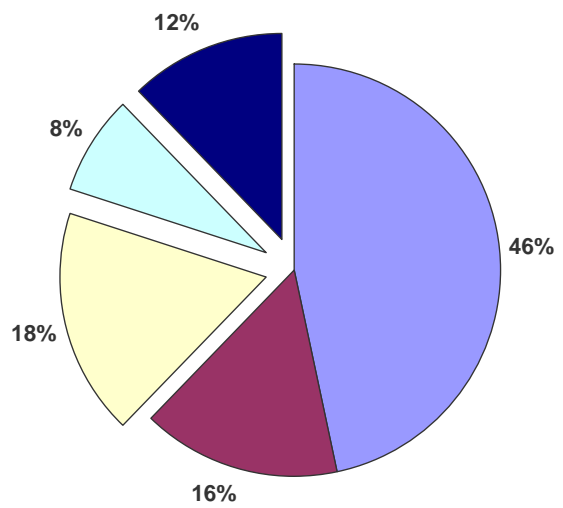
Graph 5

I feel annoyed/irritated



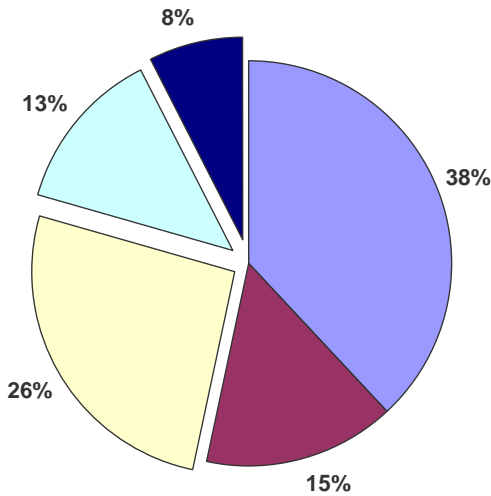
Graph 6

I feel different



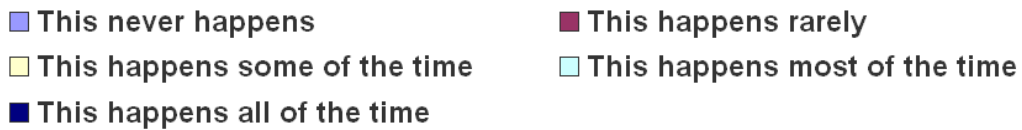
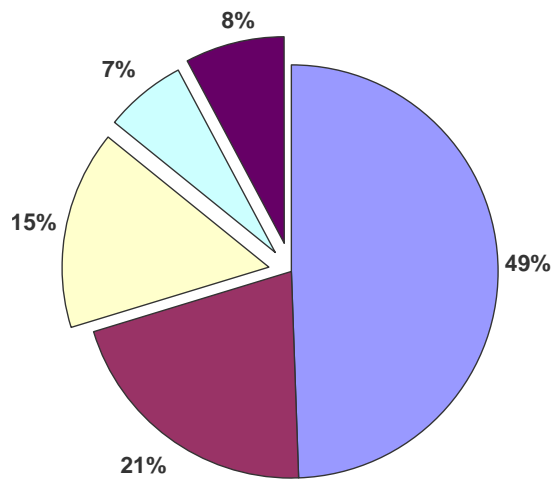
Graph 7

I feel frustrated/fed-up



Graph 8

I feel down/sad



Results

53% of respondents felt that they were proud with the way they coped with their allergies, although 47% stated they don't always feel they cope with their allergies, with 31% who did not always feel supported by family and friends, however 69% did feel supported the majority of the time by family and friends.

30% of respondents have felt down or sad as a result of living with their allergies, 36% reported having felt embarrassed, 38% reported feeling different and 47% have felt frustrated and fed up. 40% of respondents stated that living with an allergy makes them feel anxious or stressed, and 59% have felt annoyed or irritated due to their allergies.

Conclusions

The survey received a good range of respondents from across Scotland with a mix of male and females across all age ranges.

Respondents visited a health care professional yearly (26%) or twice yearly (23%), with 26% stating they never visit a health care professional for their allergies. Of the latter 26% most had hay fever (59%), which may often not be regarded as a reason to seek health care support, especially since it is seasonal only, and had been prescribed adrenaline auto-injectors.

The majority of respondents in this survey are seen in primary care (83.2%) for their allergies, with the most common allergic condition being identified as hayfever (52%).

Severe allergies affected 15% of the young people surveyed and of those with severe allergies requiring adrenaline auto-injectors, 24% felt they would not be

confident to use their adrenaline auto-injectors in an emergency and 20% of respondents felt that staff in school / college would not know what to do in a medical emergency. This indicates a need for improved allergy education for health care professionals and education staff to improve support for young people with severe and life threatening allergic conditions.

The results of this survey;

Indicate that young people would like to feel they are involved in the decision making process around their allergy care, feel that their health care professional listens to their needs and is supportive of the impact allergy has on their life and have access to appropriately qualified clinicians and good quality care delivered as locally as possible.

Highlights the impact allergies have on a young person's lifestyle, with approx 20-30% of the respondents surveyed stating they have regular problems coping with their allergies affecting their education or work performance. The survey also found that having allergies has an impact on a young person's social life on for approx half of the respondents, including bullying, problems with forming friendships and social interaction with friends, including eating out. It is widely accepted that social interaction and the development of relationships, especially with peers is a very important aspect of adolescents and young people emotional wellbeing.

Highlights that allergies can have a significant negative impact on how young people feel they cope emotionally, with between 30 to 50% of respondents having felt a range of emotions including anxiety, stress, frustration, anger, embarrassment, feeling different to peers and feelings of sadness, feeling down or fed up due to the challenges of living with an allergic condition.

Recommendations

Allergy appears to have a major impact on a significant proportion of the young people surveyed and the impact of allergy on a young person's social life both in school / college and out of school needs to be addressed. Improved support mechanisms need to be developed within the school / college environment and with health care providers to enable and empower young people to cope with their allergies and lessen the impact that allergy can have on their quality of life.

- Develop a resource pack for teachers to enable them to gain more understanding of the impact of allergy and thus provide support to vulnerable young people. The resource pack can then be used as a teaching tool within class to stimulate discussion amongst peers.
- Equip health care professionals with the knowledge and skills to improve support where required to children & young peoples with allergies and increase awareness of the impact that allergy can have on the young person's quality of life, e.g. social issues around eating where a severe food allergy is diagnosed.
- Increase the responsiveness of clinicians to the needs and wishes of young people. Deliver care with a more flexible approach to accommodate young people's needs.

- Assess the practicality of close working with health care professionals providing care in educational establishments to provide allergy awareness sessions in schools and colleges.
- Develop a clear transition pathway from paediatric allergy care / primary care to adult allergy services for allergy where appropriate.
- Improve awareness of allergy by developing methods of delivering advice and support for family, friends and the general public
e.g. develop information for the CYANS website, posters, leaflets for display in community use area .