

Action for XP

Scotland · Charity number SC045465

Details

Status Active

Legal form SCIO (Scottish Charitable Incorporated Organisation)

Registered 2015-03-06

Register [View on the OSCR register](#)

Contact

Address Westfield
Cushnie
Alford
Aberdeenshire
AB33 8LP

Website www.actionforxp.org

Activities

Activities: 'It makes grants, donations, loans, gifts or pensions to individuals','It carries out activities or services itself'

Purposes: 'the advancement of education','the advancement of health','the promotion of equality and diversity','the relief of those in need by reason of age, ill-health, disability, financial hardship or other disadvantage'

What the charity does: Action for XP is established for charitable purposes only, and in particular, the objects are: To provide a comprehensive support network for individuals and families affected by the ultra-rare disease, xeroderma pigmentosum (XP), providing equitable access to our charitable services throughout the UK. Providing both practical and emotional support to aid the improvement to the quality of life for individuals and families affected by XP, through all life stages of living with the disease. To further conditions for families in underserved regions internationally by engaging in proactive collaboration and knowledge sharing with our peers internationally. To further scientific understanding of xeroderma pigmentosum and work with the international scientific community to progress research and communicate that research to our community. To promote education and awareness both within the XP community and externally within the professional community and general population.

Beneficiaries: 'People with disabilities or health problems'

Objectives: 4 The organisation is established for charitable purposes only, and in particular, the objects are:
4.1 To provide a comprehensive support network for individuals and families affected by the ultra-rare disease, xeroderma pigmentosum (XP), providing equitable access to our charitable services throughout the UK. Providing both practical and emotional support to aid the improvement to the quality of life for individuals

and families affected by XP, through all life stages of living with the disease. 4.2 To further conditions for families in underserved regions internationally by engaging in proactive collaboration and knowledge sharing with our peers internationally. 4.3 To further scientific understanding of xeroderma pigmentosum and work with the international scientific community to progress research and communicate that research to our community. 4.4 To promote education and awareness both within the XP community and externally within the professional community and general population. 4.5 The promotion of inclusivity, diversity, equality, and awareness, operationally and across our activities

Geography

- **Main operating location:** Aberdeenshire
- **Geographical spread:** UK and overseas

Finances

Period end	Income	Expenditure	Assets	Employees
2025-03-31	£24,952	£54,859	-	2
2024-03-31	£24,840	£11,635	-	1
2023-03-31	£66,164	£23,839	-	0
2022-03-31	£5,428	£6,149	-	0
2021-03-31	£9,226	£849	-	0

Accounts

2024/25 Accounts for Action for XP SC045465**Receipts and Payments**

Receipts	2024/2025	2023/2024
Transfer from XPSG		
Schools packs		
Retail Little Ted Bears	£450.00	
Little Ted Books		
DSG/BMD books		
Big Book of Yes		£46.79
Other Income/Donations	£639.82	£930.13
Sponsored Events	£5.00	£10,882.33
XP Connect/Comic		
TT Events		
Collected Gift Aid	£36.25	£61.50
Private donations	£1,900.00	£1,970.00
Grant received	£21,921.00	£10,950.00
Loan		
TOTAL RECEIPTS	£24,952.07	£24,840.75

Payments

Charity event places		£61.20
Events		
DSG/BMD		
Travel and accommodation costs	£1,349.37	£93.85
Office costs	£4,072.55	£3,044.89
Just-giving & paypal charges	£325.97	£338.14
Insurance		
Packaging and postage	£18.00	£230.87
Marketing	£158.78	£122.34
Miscellaneous Expenses		
Donations		
Rent	£1,412.01	
Sub-contractor consultancy and support	£30.00	£2,010.00

Staff costs

Employee costs	£29,625.24	£1,800.00
Employers NI	£474.58	£39.20
Employer's Pension	£524.37	£14.40
Traning costs	£470.40	

Costs of Projects

LT Book & Bear	£3,617.00	
Patient Protection	£8,228.97	£937.90
Project Breakaway		£367.25
Travel Grants	£631.60	£1,150.80
XP Connect/Comic	£960.00	
Mental Health Support	£2,960.00	£1,425.00

Action for XP Accounts

Little Ted & Friends animation
Little Ted goes to School packs

TOTAL PAYMENTS	£54,858.84	£11,635.84
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SURPLUS/DEFICIT	-£29,906.77	<u>£13,204.91</u>
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Action for XP Statement of Balances 2024/25

	2024/2025	2023/2024
Opening Balance	£74,629.91	£61,425.00
Surplus/Deficit	-£29,906.77	£13,204.91
Closing Balance	£44,723.14	£74,629.91

Reserves	£32,476.00	£27,475.00
Remainder XP comic project grant	£2,990.00	£3,950.00
Remainder of international outreach grant	£0.00	£2,000.00

Donation for small adult Project Breakaway camp	£1,000.00	£1,000.00
BAD grant for mental health service	£5,565.00	£8,525.00
CiN grant for family event	£9,921.00	
BAD grant for website update	£1,000.00	
Operational reserve	£12,000.00	£12,000.00
Liability	£0.00	£0.00

Charity Accountant's Statement on Deficit

During the financial reporting period, the charity has recorded a deficit. This outcome is attributable to several interrelated factors:

Increased Staffing Costs: In line with our strategic decision to strengthen operational capacity and sustainability, the charity has moved to employing staff. While this investment enhances our ability to deliver services and improve governance, it has significantly increased our expenditure compared to prior years when operations were solely volunteer-led.

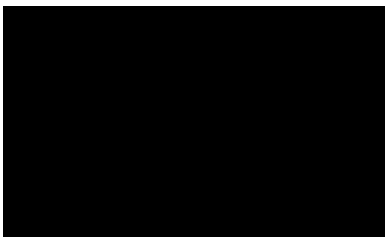
Fundraising Shortfall: Despite ongoing efforts, our fundraising activities have not generated the level of income anticipated. External factors, including a competitive funding environment and economic pressures on donors, have contributed to this shortfall. As a result, the additional costs associated with staffing have not yet been matched by corresponding increases in unrestricted income.

Delayed Grant Income: The charity has experienced delays in receiving grant payments from the NHS relating to annual awards made in 2023 and 2024. These funds, once received, will partially offset the deficit; however, the timing of payment has adversely impacted cash flow and contributed to the reported shortfall in this financial year.

Conclusion

The deficit reflects a transitional period in the charity's development, as we build organisational capacity through staffing while awaiting the resolution of delayed grant income. Our Events and Fundraising Officer, with the support of the Trustees continues to further refine the charity's fundraising strategy in the hopes that 2025/26 may see improvements. In the meantime, prudent financial management and close monitoring of expenditure continue to be prioritised.

Approved by the Trustees and signed on their behalf by



Treasurer



Annual Impact Report



Action for **XP**
Support. Educate. Connect.

1st April 2024 – 31st March 2025

Action for XP (SCIO)

Charity no: SCO45465

www.actionforxp.org

Support Educate Connect

contact us

Action for XP (SCIO)
Scottish Charitable Incorporated
Organisation: **SCO45465**

Registered address:
Westfield, Cushnie, Alford,
Aberdeenshire, AB33 8LP



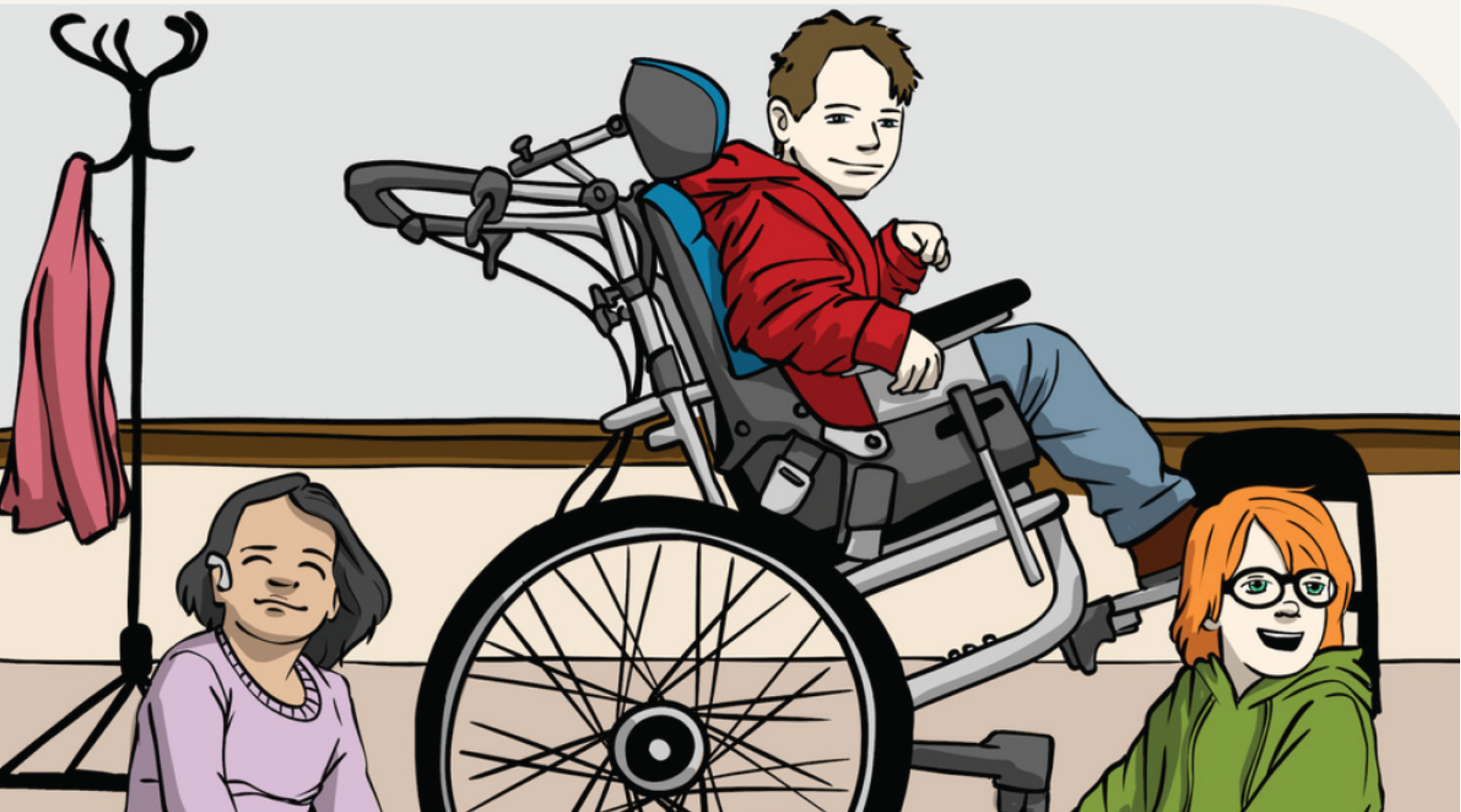
www.actionforxp.org



support.actionforxp.org



[@ActionforXP](https://www.facebook.com/ActionforXP)



Structure, governance, management, mission

Action for XP is recognised as a Scottish Registered SCIO and has a Board comprising seven Trustees. Our focus remains to **support, educate and connect**, in pursuit of improved lives for our beneficiaries.

Trustee recruitment, and resignations

There were four new trustees recruited to the board during our September recruitment drive and we welcomed [redacted]

We had four resignations from the board and we said farewell to [redacted] (who was only able to serve for a short time due to changing work commitments). We would like to extend our thanks to all for their support over their time serving on the Action for XP board.

- To provide **practical and emotional support** to individuals and families regardless of age and stage of life
- To **reach underserved regions** internationally by collaboration and knowledge sharing
- To further scientific understanding of XP through **research** and **dissemination of research**
- To provide **education and awareness** within the XP community and externally
- To promote **inclusivity, diversity and equality** operationally and across our activities

Volunteers

In addition to our board we are supported on a regular basis by the following volunteer:

[redacted] (resource dispatch)

Board of Trustees

[redacted]	Chair of the Board	Trustee, XP patient, Dermatology Registra
	Treasurer	Trustee, XP family
	Secretary	Trustee, XP family
	Trustee	Trustee, XP patient
	Trustee	Trustee, XP family
	Trustee	Trustee, XP family
	Trustee	Trustee

Letter from our *Chair*

I write this whilst sat looking out on the start of New Zealand's summer and the eye-watering high levels of UV this summertime here brings with it. I am thankful therefore for earlier diagnoses of Xeroderma Pigmentosum and expansion of our international community.

I would also like to extend a personal thank you to all those people who were in a position to be able to make regular donations this year in support of the continued operations of Action for XP.

It has been very challenging in the post-Covid landscape to secure further funding which is in very high demand. [REDACTED], our two dedicated, part-time team members have done a tremendous job from an operational perspective. I would like to remind our community therefore that any contribution, big or small goes an incredibly long way; so please do get in touch if you would like to organise fundraising events or contribute/volunteer in any other way. It would be most welcome and well-received.

Chair of Trustees, Action for XP

The year *in review*



The following resources were dispatched directly to patients across the UK and internationally by our volunteer team



29

UV protective face visors and legionnaires hats



17

Little Ted bears and story book packs sent to new forever homes



23

Pairs of UV protective gloves



7

Rolls of UV protective film

Patient resources in clinic

Action for XP provided the following resources to the **NHS National XP Service**, at the Rare Disease Centre, St Thomas' Hospital, London, to be disseminated to newly diagnosed children and adults attending the clinic.



Patient packs; containing UV protective face visors/hats and gloves to be given to newly diagnosed adults and children in clinic



Little Ted bears and story book packs for newly diagnosed children



We sent 5 specially designed UV meters to clinic to be distributed to families to help identify safe environments.



"In 2024-2025 we shipped vital life-saving UV protective patient resources to 11 different countries across the globe."

11

Patients supported in 10 **different countries**, including:

Egypt, Norway, Pakistan, Slovakia, Turkey, USA, Nepal, South Africa, India and Italy

International support included complex shipping and customs coordination for international patients.

Patient support

100s

of direct patient support via emails, telephone calls, 1-2-1 Zooms chats, Whats App and voice messages responded to! Including support for existing and newly diagnosed patients and school, nursery and work settings

32

32 fully-funded counselling sessions with RARE Minds providing mental health support for patients and caregivers

£1,174

in customs fees covered for international families in need from low income countries



Education and awareness



During the year we attended the British Association of Dermatology event. And our community featured in a number of awareness raising articles.

In the media

- **My brother, my sunshine** by [REDACTED] featured in RARE Revolution Siblings edition. <https://editions.rarerevolutionmagazine.com/html5/reader/production/default.aspx?pubname=&edid=8f1fc7de-3beb-4f05-b4d6-f7d97a72bae3&PNUM=28>
- **Visit to Canterbury Bears** <https://www.actionforxp.org/news/archives/06-2024>

In our news

- **BAD Conference overview** <https://www.actionforxp.org/news/archives/07-2024>



Our friends at Enfants de la Lune in France have been great ambassadors for Little Ted who has been frequenting their channels helping with rare disease advocacy for French patients.

Memberships and alliances

We continue to build our network of collaborators and partners through membership and alliances with the following:

- Global Skin
- British Association of Dermatologists
- RARE Revolution Charity Partner
- Global Genes Advocacy Members



Patient Support

This year, with the addition of paid staff, the work has continued to develop our core services. Shipping of patient protection packs has continued as well as providing ongoing support to families. We have also been able to continue our relationship with the specialist XP clinic at Guys and St Thomas' Hospital and provide a joined-up approach for families, attending the clinic in person when appropriate.

International demand continues to increase with patient cohorts countries such as Italy, Norway and India reaching out for our support.

The recruitment of two staff members has increased our capacity to deliver patient services and develop our fundraising infrastructure. Families continue to need our support, not only for patient protection packs but also for protection for their homes and cars to ensure that they have a safe environment in which to live and travel.

Supporting you

With our new website we have made it easier than ever to access support:

Patient support request:

www.actionforxp.org/patient-support-enquiry.html

Action advice hub:

<https://www.actionforxp.org/action-advice-hub.html>

Schools hub:

<https://www.actionforxp.org/schools-hub.html>



support.actionforxp.org

Project breakaway (recreation and leisure):

<https://www.actionforxp.org/project-breakaway.html>

Travel grant application:

http://www.actionforxp.org/uploads/1/1/0/9/11094435/medical_travel_financial_assistance_advice_final.pdf

Research and scientific advancement

Our partnership with 123Genetix continues to pioneer the use of AI-driven virtual clinical trials and stem cell-based disease modelling to accelerate drug development for rare diseases like Xeroderma Pigmentosum (XP). We now need to progress this work and have initiated discussion with Cytochroma, whose technology produces patient-specific iPSC organoids and high-throughput screening. The collaboration aims to improve early-stage drug testing, expand genome coverage, and validate new therapies aimed at delaying or halting neurological progression, ethically and efficiently.

Despite promising technology, progress has been hindered by funding challenges. Limited financial support has delayed critical validation steps, slowed engagement with partners, and restricted infrastructure growth. As a result, the transition from proof-of-concept to scalable solutions is paused, highlighting the urgent need for strategic investment and partnerships to realize the full impact of these innovative platforms for rare disease communities.

Promotion of equality and diversity

We continued to work on our XP and Me comic project. Incorporating new stories around sport and leisure shared by members of our teen community.

Work is ongoing for the final phase of this project to be completed in 2025.



Fundraising Update

This year has brought both challenges and small but meaningful wins for Action for XP. Like many small charities, we continue to navigate a difficult fundraising landscape, with limited grant opportunities and growing competition for funds. Despite these obstacles, our determination to sustain and grow our support for the XP community remains strong.

Community fundraising is a growing area of focus for us. Although we're still in the early stages of building wider connections, we're incredibly grateful to the individuals and families within our community who have reached out to ask for help on how to take part in future fundraising activities on our behalf.

Every effort, no matter how big or small, makes a real difference and helps keep our mission moving forward.

We were also fortunate to receive a few successful grants this year, including funding from the British Association of Dermatologists (BAD) for our website redevelopment and a GlobalSkin grant to support the translation of our Little Ted books enabling more families around the world to access vital information in their own language.

Although fundraising remains a challenge, we continue to adapt, learn, and explore new ways to connect with supporters and funders.

Our commitment to those affected by XP remains unwavering, and with each small success, we move closer to creating a stronger, more sustainable future for our charity and the families we serve.

Building partnerships

The NHS funded Xeroderma Pigmentosum (XP) Multi-Disciplinary clinic was established in April 2010 to provide expert clinical care for patients thought to have or diagnosed with XP.

Action for XP is an integral part of the service giving feedback on the patient experience of the service as well as **providing and funding** photo protection, Little Ted education packs and UV meters, distributed at clinic. We also provide financial assistance for patients to attend the clinic and fund the mental health counselling service.

For further information please visit

<https://www.guysandstthomas.nhs.uk/our-services/xeroderma-pigmentosum-xp>

support@actionforxp.org

www.actionforxp.org

Finances *in review*

This year has continued to be a financially challenging year.

Community funding hit an all time low, with no income coming from community fundraising, a first in our 13 year history. This reflects the immense pressure our community face with the current cost of living crisis. We are extremely grateful to our small but dedicated private donors, collectively raising £1,900.

Our fundraising officer's efforts yielded successful results, securing four grants: A total of £11,000 from Clinuvel across two grants in the year to support photo protection, £1,000 from the British Association of Dermatology to allow us to update our website and £9,921 from Children in Need for much needed core running costs.

The largest costs this year relate to vital staffing costs, alongside patient photoprotection, Little Ted Book and Bear project and our mental health support service.

We close the accounts with a year-end deficit of -£29,906.77. This reflects the continued challenges for small charities in both raising funds through community fundraising and grant giving and increased costs. Grant givers are recording higher numbers of applications and we are finding eligibility criteria is becoming increasingly exclusive of small ultra-rare disease organisations like ours who operate on a global level.



rebecca.actionforxp.org

Funding summary

£3,031.07

Donations,
giving back

£21,921.00

Grant funding

£54,858.84

Expenditure

£44,723.14

Closing
balance

Projects costs *at a glance*



Patient Protection
(hats/visors, gloves,
film, UV meters)

£8,229



Travel Grants

£631



Little Ted Book and
Bear project

£3,617



Mental Health
Support

£2,960



XP Comic Book
project

£960

Leave a gift *in your will*

Could you leave a
gift in your will ?



"Leaving a gift in your will helps secure our services long into the future, creating a lasting legacy for the global xeroderma pigmentosum community."

IF YOU WOULD LIKE TO SPEAK TO
SOMEONE ABOUT LEAVING A
GIFT IN YOUR WILL OR TO MAKE A
REGULAR DONATION NOW
PLEASE GET IN TOUCH WITH
VICTORIA ON:



fundraising@actionforxp.org



The future...

The next 12 months will be pivotal for Action for XP as our small but dedicated team look to both support our community and balance funds.

We foresee a challenging financial time ahead which is echoed across small charities in the UK. That said our terrific team and board and working hard to ensure that we can meet our aims.

Our priorities for 2025–2026 will include the following:

- Stabilising funds to meet the needs of our operational and financial strategy.
- Developing phase 2 of the teen comic project and expanding youth engagement.
- Continue to support families with photoprotection and social support
- Continuing community engagement to understand the priorities of our diverse community.
- Build on the initial success of the mental health support project to develop group programs that complement the one-to-one counselling service.

We are committed to achieving these goals and look forward to the positive impact they will have on our community

Teen comic feedback



" *I really enjoyed sharing my story with the comic book creators to show how young people can still participate in sports and hobbies. I also really enjoyed learning about the experiences of the others who took part"*

Teen comic participant feedback



We'd like to thank all our donors for their generous *support*



Acknowledgements

Special thanks to this year's grant funders:

Children in Need

The British Association of Dermatology
Clinuvel

With thanks to our private donors:



APPENDIX 3



		Independent examiner's report on the accounts						V2
Report to the trustees/members of		Charity name Action for XP						
Registered charity number		SC045465						
On the accounts of the charity for the period		Period start date				Period end date		
		Day	Month	Year		Day	Month	Year
		01	04	2024	to	31	03	2025
Set out on pages								(remember to include the page numbers of additional sheets)
Respective responsibilities of trustees and examiner		The charity's trustees are responsible for the preparation of the accounts in accordance with the terms of the Charities and Trustee Investment (Scotland) 2005 Act and the Charities Accounts (Scotland) Regulations 2006. The charity trustees consider that the audit requirement of Regulation 10(1) (d) of the Accounts Regulations does not apply. It is my responsibility to examine the accounts as required under section 44(1) (c) of the Act and to state whether particular matters have come to my attention.						
Basis of independent examiner's statement		My examination is carried out in accordance with Regulation 11 of the Charities Accounts (Scotland) Regulations 2006. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts and seeks explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit and, consequently, I do not express an audit opinion on the accounts.						
Independent examiner's statement		In the course of my examination, no matter has come to my attention [other than that disclosed on the attached page*]						
		1. which gives me reasonable cause to believe that in any material respect the requirements: - to keep accounting records in accordance with section 44(1) (a) of the 2005 Act and Regulation 4 of the 2006 Accounts Regulations, and - to prepare accounts which accord with the accounting records and comply with Regulation 9 of the 2006 Accounts Regulations have not been met, or						
		2. to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.						
Signed:							Date:	8-10-25
Name:								
Relevant professional qualification(s) or body (if any):								
Address:								

*Please delete the words in the brackets if they do not apply. If the words do apply, set out those matters which have come to your attention on the following page.

APPENDIX 3

Disclosure section

Only complete if the examiner needs to highlight material problems.

Give here brief details of any items that the examiner wishes to disclose

Independent examiner's report on the	Report to the Investment Committee of the Board of Directors
Period of the audit	Period of the audit
Set out on page	Set out on page
Responsible for the audit	Responsible for the audit
Responsible for the audit	Responsible for the audit
Responsible for the audit	Responsible for the audit
Responsible for the audit	Responsible for the audit
Responsible for the audit	Responsible for the audit