



Huntington's
Disease
Association

Information management policy

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Introduction

The Huntington's Disease Association provides advice, information and support to people affected by Huntington's disease throughout England and Wales. We hold and process information relating to those that use our services, our supporters, staff, volunteers and partnership organisations.

All information records have a life cycle - Creation - Use and Maintenance - Storage - destruction or permanent retention.

This policy outlines the principles we apply in managing information through its lifecycle. It should be read alongside the charity's Data Protection policy.

Scope

This policy applies to all people working for the Huntington's Disease Association or on behalf of the Huntington's Disease Association in any capacity, including employees, trustees, agency workers, seconded workers, volunteers, contractors and suppliers.

All these groups need to be aware of confidentiality issues surrounding retention, access to and disposal of records.

This policy applies to all information recorded in the day-to-day operational functioning of the charity, whether electronic or paper.

Our commitment

The Huntington's Disease Association is committed to ensuring the following key principles in relation to its management of information:

- Managing information in accordance with current information and data protection legislation.
- Managing information in accordance with relevant regulation. As a charity as well as a company limited by guarantee, the Huntington's Disease Association falls under regulation of both Companies House and the Charity Commission.
- Establishing standardised, effective, efficient and secure records management practice for paper and electronic records.
- Ensuring information is destroyed in line with clearly defined retention periods appropriate to their significance and legislative requirements.
- Ensuring information is retained as required to fulfil relevant statutory requirements.

Record keeping is vital for good governance and necessary for complying with the wide range of regulations that apply to charities in England and Wales. Good record keeping will:

- Show that we are complying with regulation.
- Provide evidence of how we have made decisions and demonstrate good governance and processes.
- Make day-to-day work more efficient as staff members, trustees and volunteers know where to find information.
- Make it easier to show the impact of our charity.
- Build trust with those that we work with, our supporters, donors, funders, regulators and the public so they know we treat their information with respect and can be held accountable for our actions and decisions.

Responsibilities

Board of trustees

The Board of trustees is responsible for information management within the charity and must ensure provision is made for any statutory or other requirements to be met. The Board must understand how information is managed across the charity. Clear lines of accountability exist at Board level and throughout the organisation as documented in the charity's Governance handbook and scheme of delegation.

Information management issues that could pose a risk to the charity should be reported to the Board, e.g. loss or misuse of data, serious noncompliance that has been escalated through Disciplinary process and has led to suspension or dismissal, data breaches. Data protection is a standing agenda item at all board meetings for such issues to be raised and discussed.

Management

The management team must ensure that staff in their area of responsibility understand and are compliant with the information management policy and practice.

Managers are required to ensure that all staff are aware of information management processes as it relates to their day-to-day workload. This includes:

- how to create information records
- how to store information securely as appropriate
- how long to hold various information records
- confidentiality and who may and may not have access to various information records
- how information is transferred or shared
- when to dispose of information records
- how to dispose of information records appropriately

All employees

Staff are required to understand the types of records they manage and the appropriate usage, storage and disposal of these, as above.

An element of information management will be included in the induction programme for new staff as part of the relevant Data Protection training for the individual role. Appropriate training should be sought where required to assist staff and managers in fulfilling their duties under this policy.

Volunteers

Volunteers are required to create and store records in accordance with the organisation's Data Protection and Information Management policies as relevant.

Contractors and suppliers

For any contractors and suppliers who process information on behalf of the charity, such as financial accountants, auditors, payroll, human resources, IT support agencies, there must be a formal agreement in place outlining the secure processing, storage and retention periods of any information records they hold.

Information records

The Huntington's Disease Association holds a number of different types of records, as detailed further in the retention and destruction schedule within this policy.

Information and record creation

The Huntington's Disease Association retains information and creates records to provide evidence of our decisions, activities and actions.

Records should be created, with relevant content to meet our need for evidence and information to carry out our activities, particularly where there are external legal or regulatory requirements.

Records must be created or captured in a form that will enable us to access relevant information for the full length of their retention period.

Where records created or captured contain personal information this information must be relevant to their purpose and not excessive. Records should be maintained accordingly.

Information should be sufficiently detailed, accessible and understandable, avoiding jargon wherever possible. Recording that is based on third party information will be acknowledged as such. Information records should not include speculation or opinion. Information records should contain a clear explanation of any intervention or actions taken.

Information and record storage

Having organised and well-managed records enables us to provide relevant information, advice and support to those who use our services and support us and respond quickly and efficiently to requests for information which may come from a range of regulators, funders and stakeholders.

It is imperative that information and records are stored securely, whether in electronic or paper format. Relevant financial information and details relating to supporters, members, volunteers and those who access our services, should be stored securely within the relevant charity database or information storage system contained within the charity's secure server. Where confidential and personal information is stored electronically by staff, it will be stored on a secure server with password protection / encryption in place with access details shared only with those authorised to view the information to prevent unauthorised access. Where electronic storage of information is not possible, paper records of a confidential nature should be held in a locked filing cabinet, cabinet or drawer and should not be taken off the premises without prior agreement from a staff member's line manager,

Information and record retention

Information records must be retained in line with the Huntington's Disease Association's data retention and destruction schedule. This schedule ensures that information retained by the charity is kept for only as long as is necessary to enable us to carry out relevant activity and comply with regulation.

Information records should be reviewed against the charity's data retention and destruction schedule on an annual basis (see appendix 1).

Records that have passed their retention period and have no current requirement to retain the information, such as a current or pending legal action, safeguarding concern or complaint, should be securely disposed of by the relevant data owner.

Information records may be sent to an approved archiving facility for permanent retention depending on their content or destruction after a particular time period in line with the retention and destruction schedule. This should be arranged through liaison with the charity's Operations team who will require records to be sent to them with a completed archiving slip per file containing details of the content and retention period.

Information and record access

The Huntington's Disease Association takes the privacy of our beneficiaries, supporters, members, volunteers and employees very seriously and is committed to openness, avoiding unnecessary secrecy and bureaucracy, and ensuring individual privacy is respected.

We are committed to ensuring that all personal data and sensitive organisational information is treated confidentially whilst complying with the law regarding the protection and disclosure of information.

Staff will have access to the information that they need to know to carry out their work and are under a duty to respect the confidentiality of all personal data held by the charity.

All employed staff, temporary workers and volunteers must sign a confidentiality agreement before being given access to any personal information held by the charity. For paid staff this agreement forms part of their contract of employment. For volunteers, it is covered by the charity's confidentiality form or by the Branch or support group agreement documentation.

In accordance with General Data Protection Regulation (GDPR), data subjects, in other words those we hold data about, have a right to access the information we may retain about them, to have it deleted and to have it rectified in cases of inaccuracy. The Data Protection Policy should be read for full details about the individual's rights and the processes in place.

Information and record sharing

Information should only be shared with other agencies or organisations where an individual has given permission. However, personal information may need to be shared with the police and other agencies if we have concerns about the person or if there is a risk to life, a risk that someone may be harmed or we are required to do so to comply with legislation or regulatory requirements.

Information about employees or volunteers may be shared with third parties in order to facilitate relevant charity processes such as payroll, employment law advice and DBS checks in line with the formal agreements and contracts in place.

Information and record disposal

The relevant data owner in line with the data retention and destruction schedule must destroy information records securely. Where records are scheduled for destruction but there is a current requirement to retain the information, such as a current or pending legal action, safeguarding concern or complaint, destruction should be delayed until the relevant activity has been concluded.

Paper information, will be treated as confidential waste and should be shredded by the data owner or disposed of by an authorised contractor in a confidential manner. Electronic records, including emails, should be deleted and the recycle bin emptied where relevant.

Where the retention of some data is required for historical record keeping of the charity's data, personal data should be deleted and records should be anonymised.

All computers and mobile phones that are no longer in use are wiped and securely destroyed to ensure no unauthorised access can occur.

Retention and destruction schedule

Type of information	Document	Retention Period	Reason for retention	Data owner
Governance	Governing documents (Memorandum and Articles of Association, Charity certificate)	Permanently – both original and updated copies	Companies Act, Charities Act	Chief Executive
Governance	Certificate of Incorporation and Certificates on Change of Name	Permanently	Companies Act, Charities Act	Chief Executive
Governance	Information submitted to the register of charities / Charity Commission	Permanently	Companies Act, Charities Act	Treasurer
Governance	Copies of resolutions submitted to Companies House	Permanently	Companies Act, Charities Act	Treasurer
Governance	Minutes of Trustee meetings	Permanently	Recommended Best Practice	Chief Executive
Governance	Minutes of committee meetings	Permanently	Recommended Best Practice	Chief Executive
Governance	Minutes of Annual General Meetings or Extraordinary General Meetings	Permanently	Recommended Best Practice	Chief Executive
Governance	Proxy voting forms	One year after general meeting	Companies Act	Chief Executive
Governance	Major agreements of historical significance	Permanently	Recommended Best Practice	Chief Executive
Governance	Trustee appointments <i>Election results, signed contracts /</i>	Permanently	Charities Act 2011, Companies Act 2006	Chief Executive

	<i>declarations</i>			
Governance	Register of trustees / directors	Permanently	Companies Act	Chief Executive
Governance	Trustee register of interest records	Permanently	Companies Act	Chief executive
Governance	<p>Register of voting members</p> <p><i>This will include the details of:</i></p> <ul style="list-style-type: none"> <i>the names and addresses of the members</i> <i>when each person was registered as a member</i> <i>when any person ceased to be a member</i> 	Permanently	Charities Act 2011, Companies Act 2006	Chief Executive
Governance	Annual accounts and annual report	Permanently	Recommended Best Practice	Chief Executive
Governance	<p>Policy and strategy documents</p> <ul style="list-style-type: none"> Charity business plans and strategies Policies and procedures Risk register Scheme of delegation 	Permanently	Recommended Best Practice	Chief Executive
Governance	Organisational charts	Permanently	Recommended Best Practice	Chief Executive
Governance	Complaints	Six years from completion of the investigation	Recommended Best Practice	Chief Executive

		Unless relating to a child protection – see 'Child Protection records' and 'Concerns about an adult records' for further information.		
Governance	Leases	12 years after the lease and liabilities under the lease have been terminated	Limitations Act 1980	Chief Executive
Governance	Property deeds, planning consents and building certifications	Permanently	Limitations Act 1980	Chief Executive
Governance	Contracts with suppliers	6 years after expiry of termination of the contract. If the contract is executed as a deed, the limitation period is twelve years	Limitations Act 1980	Chief Executive
Governance	Joint working / partnership agreements	Six years from conclusion of the relationship	Limitations Act 1980	Chief Executive
Health and Safety	Health and safety records e.g. details of Injuries or Accident Reports and general health and safety logs and risk assessments	For accident / incident reports - 3 years from time of occurrence or if the accident / incident involves a child / young adult, then until that person reaches the age of 21.	The Reporting of Injuries, Diseases and Dangerous Occurrences Regulations 1995 (RIDDOR) and Limitation Act 1980. Special rules apply concerning incidents involving hazardous	Chief Executive

		<p>Risk assessment records should be kept as long as the particular process or activity, to which the assessments refer, is performed and for three years after.</p> <p>For any records relating to hazardous substances – these should be retained for 40 years from the time of occurrence.</p>	<p>substances - The Control of Substances Hazardous to Health Regulations 1999 and 2002 (COSHH)</p> <p>Personal injury actions must generally be commenced within 3 years of injury. However industrial injuries not capable of detection within that period (eg asbestos) may have the time period extended.</p>	
Health and Safety	Records of tests and examinations of control systems and protective equipment under the Control of Substances Hazardous to Health Regulations (COSHH)	Five years from the date on which the tests were carried out	The Control of Substances Hazardous to Health Regulations 1999 and 2002 (COSHH)	Chief Executive
Health and Safety	First aid training	Six years after employee has left employment	Health and Safety (First Aid) Regulations 1981.	Chief Executive
Health and Safety	Fire Warden Training	Six years after employee has left employment	Fire Precautions (Workplace) Regulations 1997	Chief Executive
Health and Safety	General staff health and safety training	Six years after employee has left employment	Health and Safety (Consultation with Employees) Regulations 1996; Health and Safety Information for Employees	Chief Executive

			Regulations 1989	
Finance	Welfare grants awarded	<p>Six years from the end of the financial year in which the grant was processed</p> <p>A record that a grant was awarded or unsuccessful, where the individual is a service user with a FileMaker record, this will be retained for six years from the date the person ceased to be an active client on the FileMaker</p>	Limitation Act 1980	Chief Executive
Finance	Research grants	Permanently	<p>Recommended Best Practice</p> <p>Data Protection Act permits the keeping of such information for historical / statistical purposes</p>	Chief Executive
Finance	Accounting records	Six years from the end of the tax year to which they relate	Section 221 of the Companies Act 1985 as modified by the	Financial Accountant

			Companies Acts 1989 and 2006	
Finance	Employers Liability insurance certificate	Permanently	Employers Liability (Compulsory Insurance) Regulations 1998	Chief Executive
Finance	Public Liability Policies	Permanently	Recommended Best Practice	Chief Executive
Finance	Sundry insurance policies, claims and correspondence	Three years after lapse or after settlement	Recommended Best Practice	Chief Executive
Finance	Invoice – Capital item	10 years	Companies Act / Charities Act and HMRC	Head of Operations / Financial Accountant
Finance	Successful quotations for capital expenditure	Permanently	Commercial considerations	Chief Executive
Finance	Invoice – Revenue	6 years from the end of the financial year in which the transaction was made	Companies Act / Charities Act	Head of Operations / Financial Accountant
Finance	Payments cash book or record of payments made	6 years from the end of the financial year in which the transaction was made	Companies Act / Charities Act	Head of Operations / Financial Accountant
Finance	Purchase Ledger	6 years from the end of the financial year in which the Transaction was made	Companies Act / Charities Act	Head of Operations / Financial Accountant
Finance	Petty Cash Records	6 years from the end of the financial year in	Companies Act / Charities Act	Head of Operations /

		which the transaction was made		Financial Accountant
Finance	Bank paying in counterfoils	6 years from the end of the financial year in which the transaction was made	Companies Act / Charities Act	Head of Operations / Financial Accountant
Finance	Bank statements	6 years from the end of the financial year in which the transaction was made	Companies Act / Charities Act	Head of Operations / Financial Accountant
Finance	Remittance advices	6 years from the end of the financial year in which the transaction was made	Companies Act / Charities Act	Head of Operations / Financial Accountant
Finance	Bank reconciliations	6 years from the end of the financial year in which the transaction was made	Companies Act / Charities Act	Head of Operations / Financial Accountant
Finance	Receipts cash book	6 years from the end of the financial year in which the transaction was made	Companies Act / Charities Act and HMRC	Head of Operations / Financial Accountant
Finance	Sales Ledger	6 years from the end of the financial year in which the transaction was made	Companies Act / Charities Act and HMRC	Head of Operations / Financial Accountant
Finance	Investment ledger	Permanently	Companies Act, Charities Act, commercial	Treasurer / Financial Accountant

Finance	Investment certificates	Permanently	Companies Act, Charities Act, commercial	Treasurer / Financial Accountant / Chief Executive
Finance	Fixed assets register	Permanently	Companies Act, Charities Act, commercial	Chief Executive / Financial Accountant
Finance	Branch, support group and volunteer finance returns, receipts and expenses	6 years from the end of the financial year in which the financial information relates	Taxes Management Act 1970	Financial Accountant / Head of Operations / Head of Fundraising
Finance	Correspondence re donations	6 years from the end of the financial year in which the transaction was made	Companies Act / Charities Act Taxes Management Act 1970	Head of Fundraising / Financial Accountant
Finance	Trust, Foundation and Statutory Grant agreements and payments received	Six years after funding has ended or longer if contract demands	Taxes Management Act 1970	Head of Fundraising
Finance	Sponsors	Financial information should be retained for six years from the date of sponsorship Sponsor contact	Taxes Management Act 1970	Head of Fundraising

		<p>information should be used / retained for the purposes of communicating sponsorship opportunities until such point that the sponsor opts out of such communication or until it is no longer relevant to either party.</p>		
Finance	Deeds of covenant/Gift Aid records and declarations	<p>6 years from the end of the accounting period they relate to.</p> <p>12 years if payments outstanding or dispute regarding the deed</p> <p>If there are any enduring declarations covering regular donations, eg a direct debit or standing order, they should be kept permanently. If a donor stops their donations, then the six year time limit applies from the date of the final donation.</p>	Recommended Best Practice	Head of Fundraising / Head of Operations

		<p>If a single declaration applies to more than one donation, work out when the last donation was received and keep the declaration for the required time from that point.</p>		
Finance	Legacies	<p>The records of Donors who have expressed an interest in leaving a gift in their Will to the Huntington's disease Association should be kept until they expressly state that they will not be leaving such a gift or until four full financial years have elapsed from our notification of their death. This will enable us to identify the correlation between expressions of interest and subsequent actions.</p>	Recommended Best Practice	Head of Fundraising

		Information required for the purpose of legacy administration will be retained for six years after the estate has been wound up.		
Human Resources	Salary records including overtime, bonuses, benefits and expenses	Six years from the end of the tax year to which they relate	Taxes Management Act 1970 Finance Act 1998 Companies Act / Charities Act	Chief Executive / Financial Accountant
Human Resources	Pay As You Earn (PAYE) records, including: <ul style="list-style-type: none"> • Wage sheets • Deductions working sheets • Calculations of the PAYE income of employees and relevant payments 	Six years after employment ends	Income Tax Regulations 2003	Financial Accountant / Contracted Payroll Provider
Human Resources	Details of benefits in kind, income tax records (P45, P60, P58, P48 etc), annual return of taxable pay and tax paid	Six years after employment ends	Taxes Management Act 1970	Financial Accountant / Contracted Payroll Provider
Human Resources	Income tax and NI returns, income tax records and supporting correspondence with HMRC	Six years from the end of the tax year to which they relate	The Income Tax (Employments) Regulations 1993	Financial accountant / Contracted Payroll Provider

Human Resources	National minimum wage records	Six years after the end of the pay reference period	National Minimum Wage Regulations 2015	Financial accountant / Contracted Payroll Provider
Human Resources	Statutory maternity pay records, calculations, certificates (MatB1) or other medical evidence	3 years after the end of the tax year in which the maternity period ends	The Statutory Maternity Pay (General) Regulations 1986	Chief Executive / Financial Accountant / Contracted Payroll Provider
Human Resources	Statutory Sick Pay records, calculations, certificates, self-certificates, occupational health reports	Six years after employee has left employment	The Statutory Sick Pay Regulations 2014 abolished the former obligation on employers to keep these records. Although there is no longer a specific statutory retention period, employers must still keep sickness records to best suit their business needs. It is advisable to keep records for at least 6 years after the employment ceases in case of claims such as disability discrimination, breach of employment or personal injury and In case HMRC wish to confirm statutory sick pay has been / is being paid.	Chief Executive / Financial Accountant / Contracted Payroll Provider

Human Resources	Records of pension contributions deducted	Six years after employee has left employment	Taxes Management Act	Financial Accountant / Contracted Payroll Provider
Human Resources	Pension scheme information	Permanently	Recommended practice	Chief Executive
Human Resources	Records relating to working time	2 years from the date on which they were made	The Working Time Regulations	Chief Executive
Human Resources	Records relating to children (anyone over age of 16 when employed)	Until the child reaches the age of 21	Limitation Act 1980	Chief Executive
Human Resources	Recruitment information - successful applicants	Six years after employment has ceased See 'personnel, employment and training records' for further details	Limitation Act 1980	Chief Executive
Human Resources	Recruitment information - unsuccessful applicants Such as Job application forms, CVs, references, interview notes, safer recruitment form	One year after unsuccessful applicant notified of outcome	Equality Act 1980	Chief Executive

Human Resources	Recruitment information - Equal opportunity monitoring forms	Until data has been reviewed Data is anonymised so GDPR does not apply	Recommended practice	Chief Executive
Human Resources	Recruitment information - right to work in the UK checks	Two years after employment ends	Home Office recommended practice	Chief Executive
Human Resources	Personnel, employment and training records <ul style="list-style-type: none"> • <i>Contracts and changes to terms and conditions of employment</i> • <i>Job description</i> • <i>Safer recruitment form</i> • <i>CVs / Application forms, references and interview notes</i> • <i>Appraisal records, objectives, performance reviews or targets agreed</i> • <i>Development/training needs and records of completed activities.</i> • <i>Probationary period reviews</i> • <i>Disciplinary and capability records</i> • <i>Formal investigations</i> • <i>Promotions and demotions</i> • <i>Working time records including overtime, annual holiday entitlement, jury service, time off for dependents</i> 	Six years after employment has ceased If the employee has had concerns raised about their conduct with children, this information should be retained for a longer period. See 'Concerns about an adult records' below for further information.	Limitation Act 1980	Chief Executive
Human Resources	Concerns about an adult records	If concerns have been raised about an adult's	Information and Records Management Society best	Chief Executive / Safeguarding

	<p><i>An accurate record should be kept if concerns have been raised about an adult who works for or volunteers with children. This could be behaviour and/ or a criminal offence that affects the welfare or safety of a child or young person. The record should include:</i></p> <ul style="list-style-type: none"> • <i>What the allegations were</i> • <i>How the allegations were followed up</i> • <i>How things were resolved</i> • <i>Any action taken</i> • <i>Decisions reached about the person's suitability to work with children</i> 	<p>conduct when working or volunteering with children, a record should be kept in their personnel file either until they reach the age of 65 or for 10 years, whichever is longer. For example:</p> <ul style="list-style-type: none"> • if someone is 60 when the investigation into the allegation is concluded, keep the records until their 70th birthday • if someone is 30 when the investigation into the allegation is concluded, keep the records until they are aged 65. <p>Records should be retained for the same amount of time regardless of whether the allegations were unfounded and if the person stops working or volunteering for the charity.</p>	practice	lead
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		<p>Keeping these records ensure the charity can give accurate information if needed.</p> <p>E.g. in response to future requests for a reference, if a future employer asks for clarification about information disclosed as part of a vetting and barring check or if allegations resurface after a period of time.</p>		
Human Resources	DBS information	<p>Copies of ID documents provided as part of the application verification process should be kept for no longer than six months after the DBS application has been submitted.</p> <p>DBS certificate information should be kept for no longer than six months to allow a recruitment decision to be made</p> <p>The charity is able to</p>	Recommended Best Practice	Chief Executive

		<p>retain the following information whilst the employee /volunteer is in post and for six years after their employment:</p> <ul style="list-style-type: none"> • The date of issue of a disclosure • The name of the subject • The type of disclosure requested • The position for which the disclosure was requested • The unique reference number of the disclosure • The details of the recruitment decision taken 		
Human Resources	Redundancy details, calculations of payments, refunds etc	Six years after employment has ceased	Recommended Best Practice	Chief Executive
Human Resources	Termination of employment information	Six years after employment has ceased	Recommended Best Practice	Chief Executive
Human Resources	Flexible working requests	18 months following any appeal. This is because a further request cannot be made for 12 months	<p>Recommended Best Practice</p> <p>No statutory retention</p>	Chief Executive

		following a request plus allowing for a 6 month tribunal limitation period on top.	period required so retention period is based on charity's own requirements	
Human Resources	Annual leave records	Six years after employment ceases	Limitation act 1980	Head of Operations
Human Resources	Parental leave records	Six years after employment ceases	Limitation Act 1980	Head of Operations
Human Resources	Sickness and absence records	Six years after employment ceases	Limitation Act 1980	Head of Operations
Human resources	Records of return to work meetings following sickness, maternity etc	Six years after employment ceases	Limitation Act 1980	Head of Operations
Human Resources	Whistle blowing documents	6 months following the outcome (if a substantiated investigation). If unsubstantiated, personal data should be removed immediately.	Public Interest disclosure Act 1998 and recommended IAPP practice	Chief Executive
Human Resources	Minutes of meetings	With the exception of board meeting minutes, meeting minutes should be retained for as long as is necessary in line with the items discussed.	Recommended Best Practice	All Heads of Department

		Any minutes that contain important information or decisions about the charity should be maintained permanently.		
Service user information	Case studies (stories of beneficiaries) unless in public domain	Up to 6 years	Recommended Best Practice	Head of Communications / Head of Fundraising / Head of Advisory Service
Service user information	Children / Young person service user records	Paper files must be retained by the relevant case manager for three years after the date of last contact / date of death as recorded on FileMaker (or within the paper file in the absence of a FileMaker record). After three years, paper files can be sent to archiving. Files sent to archiving will be destroyed after six years of the date of last contact or date of death, whichever is latest.	Recommended Best Practice	Head of Advisory Service

		<p>Electronic files must be retained for three years after the date of last contact / date of death recorded on FileMaker. After three years, electronic notes on FileMaker will be automatically flagged as 'archived'. Six years from the last contact or date of death, records will be stripped of personal information and basic information retained for the purposes of statistical analysis and charity record keeping.</p> <p>There is a longer retention period for child protection records – see below</p>		
Service user information	<p>Child Protection records</p> <p><i>If an employee has concerns about a child or young person's welfare or safety, it is vital all relevant details are recorded. This must be done regardless of whether the concerns are shared with the police or children's social care. An accurate record should be kept if there are child</i></p>	<p>Child protection records should be retained until the child is 25. In order to do this the whole of their record will be kept for this time period and a date of birth must be recorded to ensure that this can take place.</p>	<p>Keeping children safe in Education 2018</p> <p>Information and Records Management Society best practice</p>	<p>Head of Advisory Service / Safeguarding lead</p>

	<p><i>protection concerns of the following:</i></p> <ul style="list-style-type: none"> • <i>Date and time of incident / disclosure</i> • <i>Date and time of the report</i> • <i>The name and role of the person to whom the concern was originally reported and their contact details</i> • <i>the name and role of the person making the report (if this is different) and their contact details</i> • <i>the names of all parties who were involved in the incident, including any witnesses</i> • <i>the name, age and any other relevant information about the child who is the subject of the concern (including information about their parents or carers and any siblings)</i> • <i>what was said or done and by whom</i> • <i>any action taken to look into the matter</i> • <i>any further action taken (such as a referral being made)</i> • <i>the reasons why the organisation decided not to refer those concerns to a statutory agency (if relevant).</i> 	<p>Information about child protection concerns and referrals should be kept within their individual FileMaker record.</p> <p>See also 'concerns about an adult records' above for further information about child protection records relating to employees / volunteers</p>		
Service user information	Serious complaint / accident / incident relating to a child (not relating to child protection)	The child's record should be retained until the child is 25.	Recommended practice	Head of Advisory Service / Safeguarding

				lead
Service User Information	Adult Service User files	<p>Paper files must be retained by the relevant case manager for three years after the date of last contact / date of death as recorded on FileMaker (or within the paper file in the absence of a FileMaker record). After three years, paper files can be sent to archiving. Files sent to archiving will be destroyed after six years of the date of last contact or date of death, whichever is latest.</p> <p>Electronic files must be retained for three years after the date of last contact / date of death recorded on FileMaker. After three years, electronic files will be automatically flagged as 'archived'. After six years of last contact or date of death, records will be stripped of personal information and basic</p>	Recommended practice	Head of Advisory Service

		<p>information retained for the purposes of statistical analysis and charity record keeping.</p> <p>Any emails relating to the individual must be deleted after six years of the date of last contact or date of death, whichever is latest.</p>		
Service user information	Service user event information	<p>Event information can be deleted after the event apart from the following which should be retained for the periods stated:</p> <ul style="list-style-type: none"> • Programme / agenda – permanently • Attendance lists and information – for 6 years if attended by children • Risk assessments – for 6 years • Incident forms – for 6 years unless it relates to a child protection or a 	Recommended practice	Head of Advisory Service / Head of Operations

		serious accident, incident or complaint. See 'Child Protection records', 'Serious complaint, accident / incident relating to a child' and 'Concerns about an adult records' for further information about longer retention periods in these instances.		
Service user information – Information held by Branch Committee's and Support Group leaders (volunteers)	Branch and support group member information – as held by Branches and Support groups for the purposes of mailing about Huntington's Disease Association Activities	For as long as the individual is a member of the group (delete if the individual dies or asks to be removed from the mailing list)	Recommended practice	Branch Secretary and other Branch committee members if required and Support group leaders
Service user information – Information held by Branch Committee's and Support Group leaders (volunteers)	Branch and support group member information – as held by Branches and Support groups for the purposes of offering peer support to families	When an individual has died or there has been no contact for three years and there is a paper file in existence the paper file will be sent to the Operations Team for archiving (clearly marked to say the date of the last contact with the	Recommended practice	Branch Committee members and Support Group leaders

		individual or the date of death). The file will be archived and marked for destruction in six years from date of last contact. When an individual has died or there has been no contact for six years and there is an electronic file in existence this should be deleted.		
Service user Information held by Branch Committee members (volunteers)	Welfare Grants processed	Six years from the end of the financial year in which the grant was processed	Limitation Act 1980	Branch secretary and other Branch Committee members if required
Accreditation scheme information	HDA Quality Assured Accreditation scheme enquiries / applications – not progressed	Enquiry details should be retained on the log and deleted once analysis for the year has been completed and recorded as part of the charity's annual impact reporting.	Recommended practice	Head of Advisory Service
Accreditation scheme information	HDA Quality Assured Accreditation scheme enquiries / applications – progressed	Enquiry and application progress details should be included in the charity's annual impact reporting and the log details should be	Recommended practice	Head of Advisory Service

		<p>retained for six years following lapse of accreditation.</p> <p>Entry on the register of accreditation – 2 years</p> <p>Self assessment Portfolio should be kept by the charity for the duration of the assessment and then returned to the care home once the relevant observation reports have been undertaken and accreditation has been awarded / rejected (or until appeal is resolved).</p> <p>Observation reports – for the duration of the care homes involvement in the scheme and six years after.</p> <p>The above retention periods also apply for re-accreditation.</p>		
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Supporter information	<p>Register of supporters, subscribers, friends or members (For members with voting rights see above)</p> <p>Records may include but are not limited to:</p> <ul style="list-style-type: none"> - Name - Date of birth - Address - Consent and communication preferences - Transactions - Direct debit and gift / gift aid records - General correspondence - Communication history 	<p>6 years from conclusion of relationship</p> <p>This includes information held within the relevant CRM and emails.</p> <p>If the information is held only in paper notebooks and diaries, these should be retained for years from conclusion of relationship. If the information has been moved online e.g. to CRM record, then notebooks and diaries can be destroyed immediately.</p>	Taxes Management Act 1970	Head of Operations / Head of Communications / Head of Fundraising
Supporter information	Supporter event information	<p>Event information can be deleted after the event apart from the following which should be retained for the periods stated:</p> <ul style="list-style-type: none"> • Programme / agenda - permanently • Attendance lists and 	Recommended practice	Head of Fundraising / Head of Operations

		<p>information – for 6 years if attended by children</p> <ul style="list-style-type: none"> • Risk assessments – for 6 years • Incident forms – for 6 years unless it relates to a child protection or a serious accident, incident or complaint. See ‘Child Protection records’, ‘Serious complaint, accident / incident relating to a child’ and ‘Concerns about an adult records’ for further information about longer retention periods in these instances. 		
Supporter information	Competition and prize draw records, including adverts, rules and, if applicable, official answers to questions set.	Date of last event of a competition (close of competition, winner selection, expiry for winner to claim / select prize) plus typically 1-2 years.	Recommended practice	Head of Fundraising

		This should be added to a central log.		
Subscriptions and licenses	Lotteries license	Permanently	Gambling Commission Guidance	Head of Fundraising
Subscriptions and licenses	ICO membership	Permanently	ICO	Data Protection lead
Subscriptions and licenses	Umbrella organisation e.g. NCVO, Neurological Alliance, genetic Alliance UK, EHA, IHA	For as long as is relevant	Recommended Practice	Chief Executive
Communications and marketing	Publications - Newsletters, magazines, guides	Permanently	Recommended practice	Head of Communications
Communications and marketing	Material with copyright protection e.g. artistic works, recordings, films, photos and broadcasts	<p>Photographs - 70 years from the end of the calendar year in which the photographer dies. Where a photographer works by commission, they will own the copyright in the photograph unless they have assigned or sold it to the commissioner.</p> <p>Written, dramatic, musical and artistic work - 70 years from the end of the calendar year in which the last remaining author of the work dies. If the author is unknown, copyright</p>	Recommended practice	Head of Communications

		<p>will last for 70 years from end of the year in which the work was created; if it is made available to the public during that time.</p> <p>Sound and music recording - 50 years from the end of the calendar year in which the work was created. If the work is published, or otherwise made available to the public by the rights owner within that time, 70 years from the end of the year that the work was first published or made available.</p> <p>Films - 70 years from the end of the calendar year in which the last principal director, author or composer dies. If the work is of unknown authorship: 70 years from end of the year of creation, or if made available to the public in that time, 70</p>		
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		<p>years from the end of the year the film was first made available.</p> <p>Broadcasts - 50 years from the end of the calendar year in which the broadcast was made.</p> <p>Layout of published editions of written, dramatic or musical work - 25 years from the end of the calendar year in which the work was first published.</p> <p>Copyright protection starts as soon as a work is created. Once copyright has expired, anyone can use or copy your work.</p> <p>In the case of work created on behalf of a company - "<i>An employer should keep careful records of which person(s) created the work for them and any</i></p>		
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		<i>contractual agreements which were in force. The period of copyright protection will usually still be linked to the date of the death of the creator(s) - that is the employee(s)."</i> - UK Government		
Communications and marketing	Branding	<p>General information can be destroyed after 6 years from superseded.</p> <p>Logos should be retained permanently</p>	Recommended practice	Head of Communications
Communications and marketing	Photographs/videos/case studies/audio (non-copyrighted and owned by the HDA or given by non-professional e.g. a fundraiser)	<p>Within the first five years, until consent is withdrawn by the subject/s of the photograph or if the owner of the photograph (only applicable if ownership has not been assigned to the charity) recalls the image.</p> <p>After five years the image will no longer be used. If we do want to use it again, we must</p>	Recommended practice	Head of Communications

		<p>seek out re-consent.</p> <p>Images that are five years old or more are archived We must get re-consent to use again.</p> <p>Keep photo/ video/audio permissions given by parents on behalf of children for 21 years and six months.</p>		
Communications and marketing	Publicity consent forms	<p>Keep for five years and then archived unless consent is withdrawn by the subject/s or owner (only applicable if ownership has not been assigned to the charity) of the photo/video/case study/audio.</p> <p>Must seek re-consent after five years if photo/video/case study/audio wants to still be used or used again.</p>	Recommended practice based on above	Head of Communications

Communications and marketing	Website	Images/video/audio/case studies etc. should be kept on the website based on the above guidance.	Recommended practice based on above	Head of Communications
Communications and marketing	Press releases, clippings etc.	6 years from publication or longer if deemed of historical importance.	Recommended practice	Head of Communications
Volunteer management	<p>Volunteer information including contact details, insurance information, risk assessments, applications, declarations, confidentiality agreements, meeting minutes etc</p> <p><i>This relates to branches, support groups, HD Voice and other volunteers (including those on voluntary placement)</i></p>	<p>6 years from termination of relationship</p> <p>See 'Concerns about an adult record' for retention periods relating to allegations made against a volunteer working with children</p>	Limitation Act 1980	Head of Fundraising / Head of Advisory Service
Volunteer management	Unsuccessful volunteer applications – forms, CVs, vetting	6 months from decision	Recommended practice	Head of Fundraising / Head of Advisory Service
Data Protection	Data breach log	Permanently	<p>Data Protection 2018</p> <p>Recommended practice</p>	Data Protection lead
Data Protection	Subject access request responses and information provided as part of the request	1 year following completion of the request.	Data Protection Act 2018.	Data Protection lead

Data Protection	Data Protection Impact Assessments	<p>For as long as the project or processing goes on for plus six years.</p> <p>A longer retention period may be required if stipulated for insurance purposes.</p>	There is no time period outlined in the legislation. The specified retention period was advised directly by the ICO.	Data Protection lead
Monitoring and evaluation	Personal data for measurement and analysis	<p>Permanently if needed for historical reference and statistical analysis.</p> <p>Where relevant, records should be anonymised or pseudonymised</p>	Data Protection Act 2018	All Heads of Department