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People with diagnosed HIV infection apparently not in care

BHIVA in collaboration with Health Protection Agency

Aims

- Estimate numbers of people with diagnosed HIV living within the UK but not receiving care
- Explore factors associated with non-retention in care
- Work towards good practice guidance on retention.

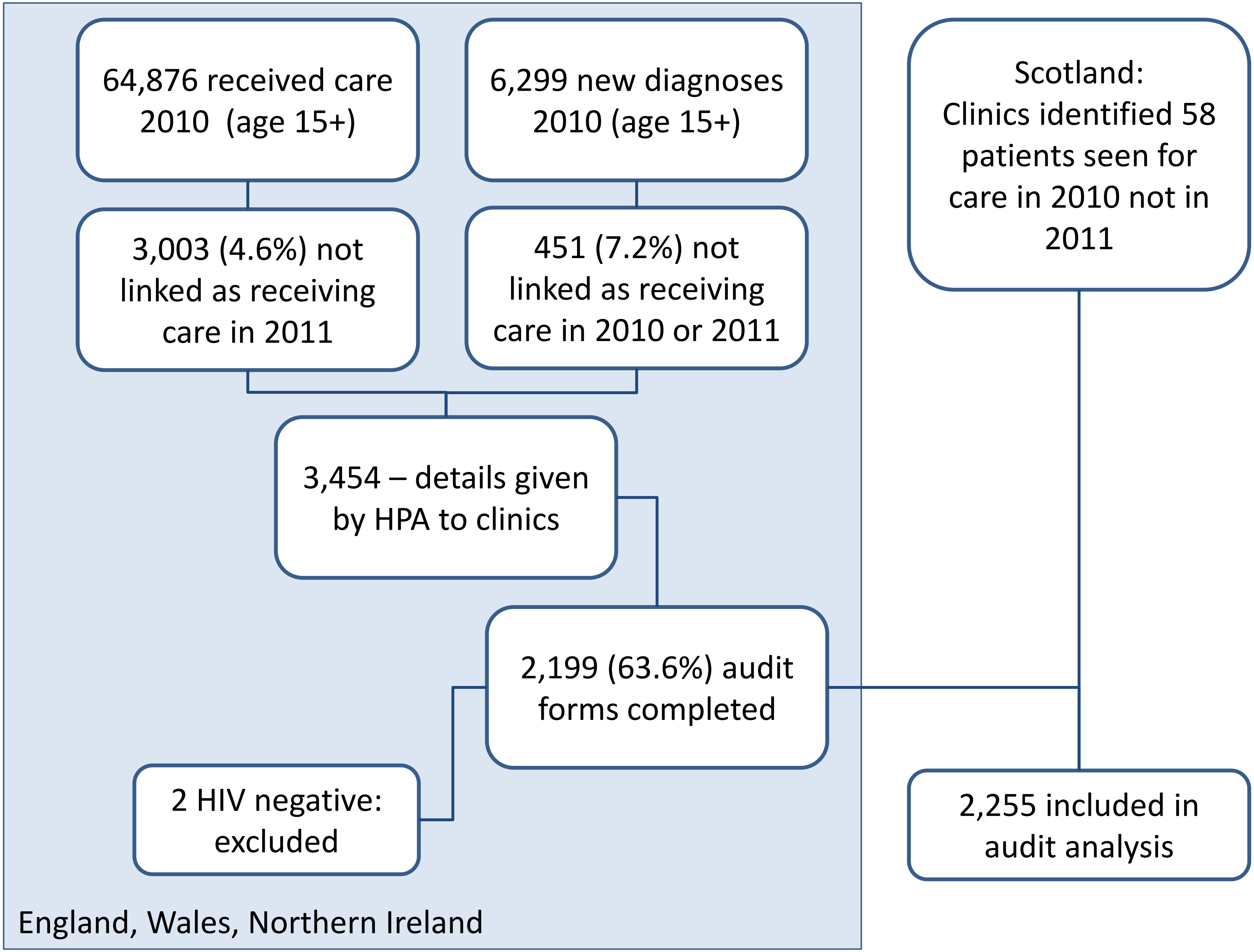
Method

England, Wales, NI: HPA used surveillance data to identify:

- Patients seen for HIV care in 2010 with no linked care report from *any* site in 2011 and no linked death report
- New diagnoses in 2010 with no linked care report from *any* site in 2010 or 2011 and no linked death report.

Scotland: Clinics identified patients seen for care in 2010 and not known to have been seen there or elsewhere in 2011.

- Casenote review of all above patients – with extended version for first 5 or 10 per site
- Survey of policy and practice on retention in care.

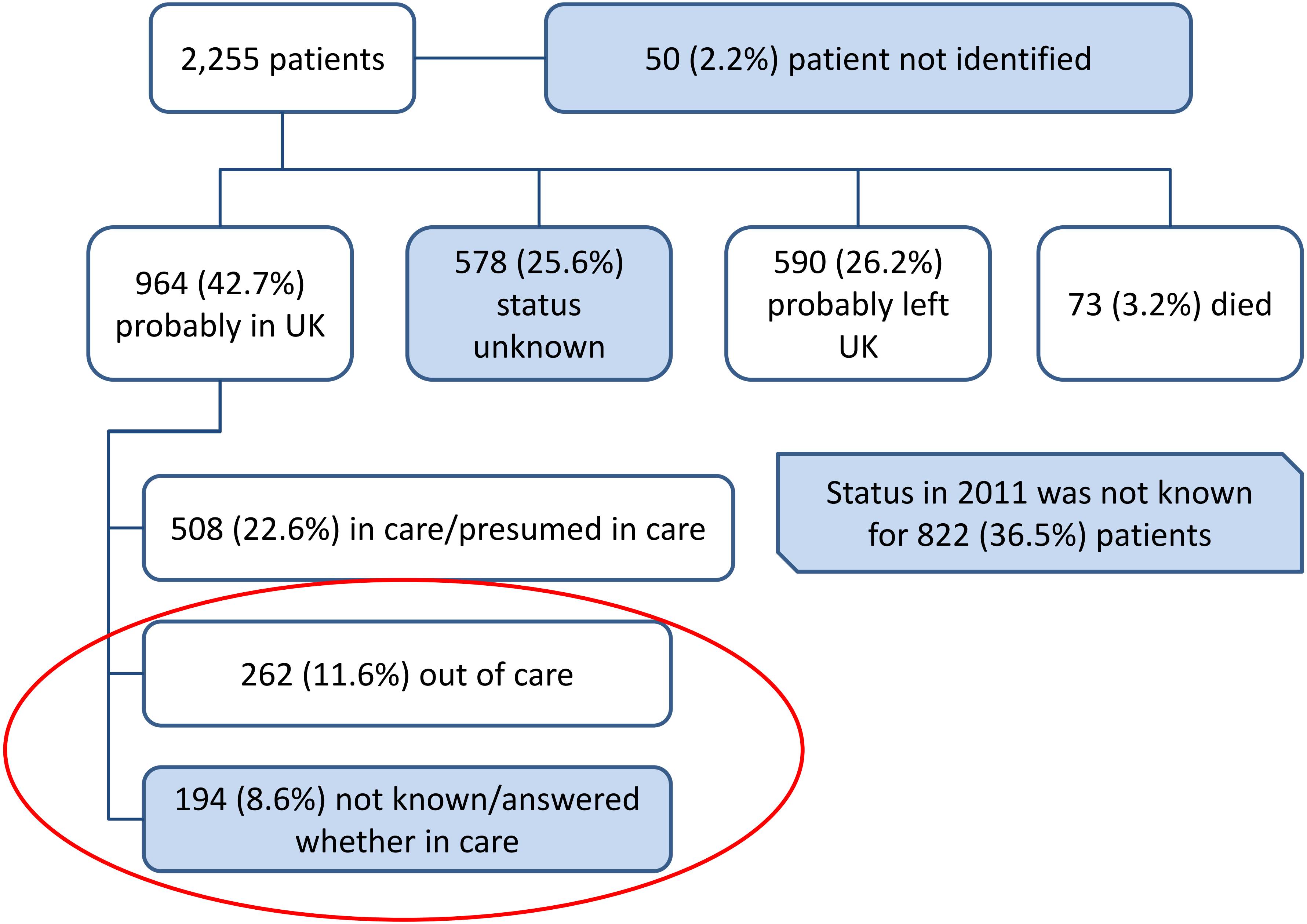

64,876 received care 2010 (age 15+)
6,299 new diagnoses 2010 (age 15+)
3,003 (4.6%) not linked as receiving care in 2011
451 (7.2%) not linked as receiving care in 2010 or 2011
3,454 – details given by HPA to clinics
2,199 (63.6%) audit forms completed
2 HIV negative: excluded
England, Wales, Northern Ireland
Scotland: Clinics identified 58 patients seen for care in 2010 not in 2011
2,255 included in audit analysis

Patient characteristics

	Audited patients: number (%)	SOPHID 2010 : %
Male	1,290 (57.2)	67
Female	838 (37.2)	33
Trans-sexual	5 (0.2)	N/A
Sex not known/stated	122 (5.4)	0
16-29	319 (14.1)	11
30-39	765 (33.9)	31
40-49	717 (31.8)	38
50+	377 (16.7)	21
Age not known/stated	77 (3.4)	0
Black-African	1,028 (45.6)	35
White	846 (37.5)	53
Other	284 (12.6)	12
Ethnicity not known/stated	97 (4.3)	1
Born in UK	600 (26.6)	New diagnoses 2010: 36
Born outside UK	1,383 (61.3)	New diagnoses 2010: 49
Birthplace not known/stated	272 (12.1)	New diagnoses 2010: 16
*Heterosexual	1,320 (58.5)	50
*MSM	726 (32.2)	44
*IDU	64 (2.8)	2
*Blood/blood products	22 (1.0)	1
*Vertical	16 (0.7)	1
*Other	11 (0.5)	2 [other/not reported]
*No known exposure category stated	134 (5.9)	

*More than one answer could be selected.

Main outcomes



2,255 patients

50 (2.2%) patient not identified

964 (42.7%) probably in UK

578 (25.6%) status unknown

590 (26.2%) probably left UK

73 (3.2%) died

508 (22.6%) in care/presumed in care

262 (11.6%) out of care

194 (8.6%) not known/answered whether in care

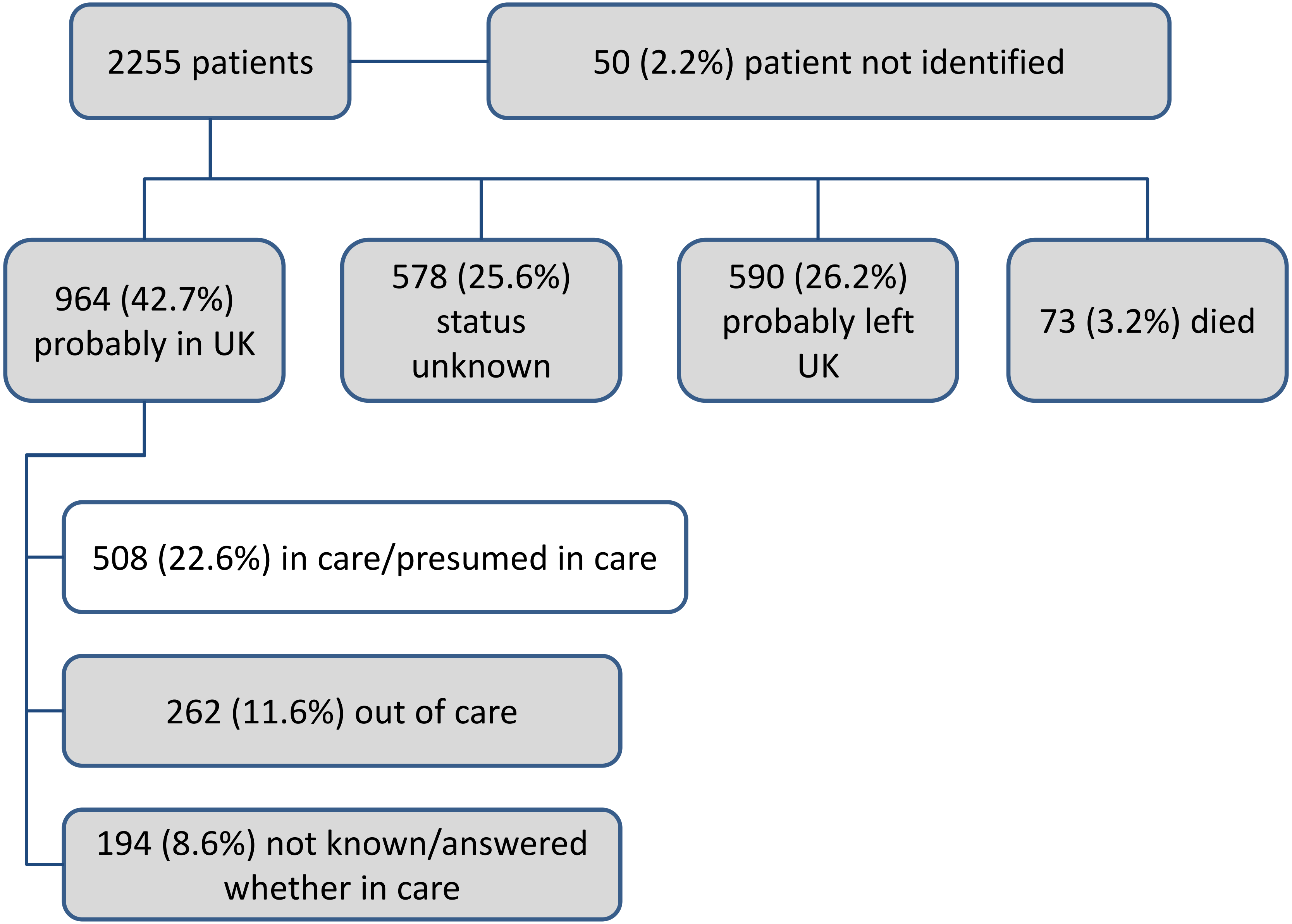
Status in 2011 was not known for 822 (36.5%) patients

456 (20.2%) patients in UK presumed out of care

Outcomes estimated as proportion of UK adults with diagnosed HIV

Outcome	Proportion of audited patients (total 2,255)	Estimated proportion of SOPHID 2010 UK adults (total 68,570)
Probably left UK	26.2%	1.4%
Died*	3.2%	0.2%
Probably in UK	42.7%	2.3%
Of whom:		
In or presumed in care	22.6%	1.2%
Not in care	**11.6%**	**0.6%**
Not known whether in care	**8.6%**	**0.5%**
Not known whether in UK	**25.6%**	**1.4%**
Patient not identified	**2.2%**	**0.1%**

*Deaths recorded as audit outcomes are additional to deaths already accounted for via SOPHID linking.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Reliability of SOPHID linking?

22.6% audited patients* were thought to still be in care in the UK, but were not linked in SOPHID.

Possible scenarios:

- Reported to SOPHID, but records not linked:

  "…seen by IDU services in same hospital - we use GUM number they use hospital number."

- Seen for care, but not reported to SOPHID:

  "Care provided by haematology service with advice from GUM … not reported to HPA."

  "attended for bloods including CD4 and VL but was not seen by a doctor"

- Presumed in care at another clinic, but may not have attended:

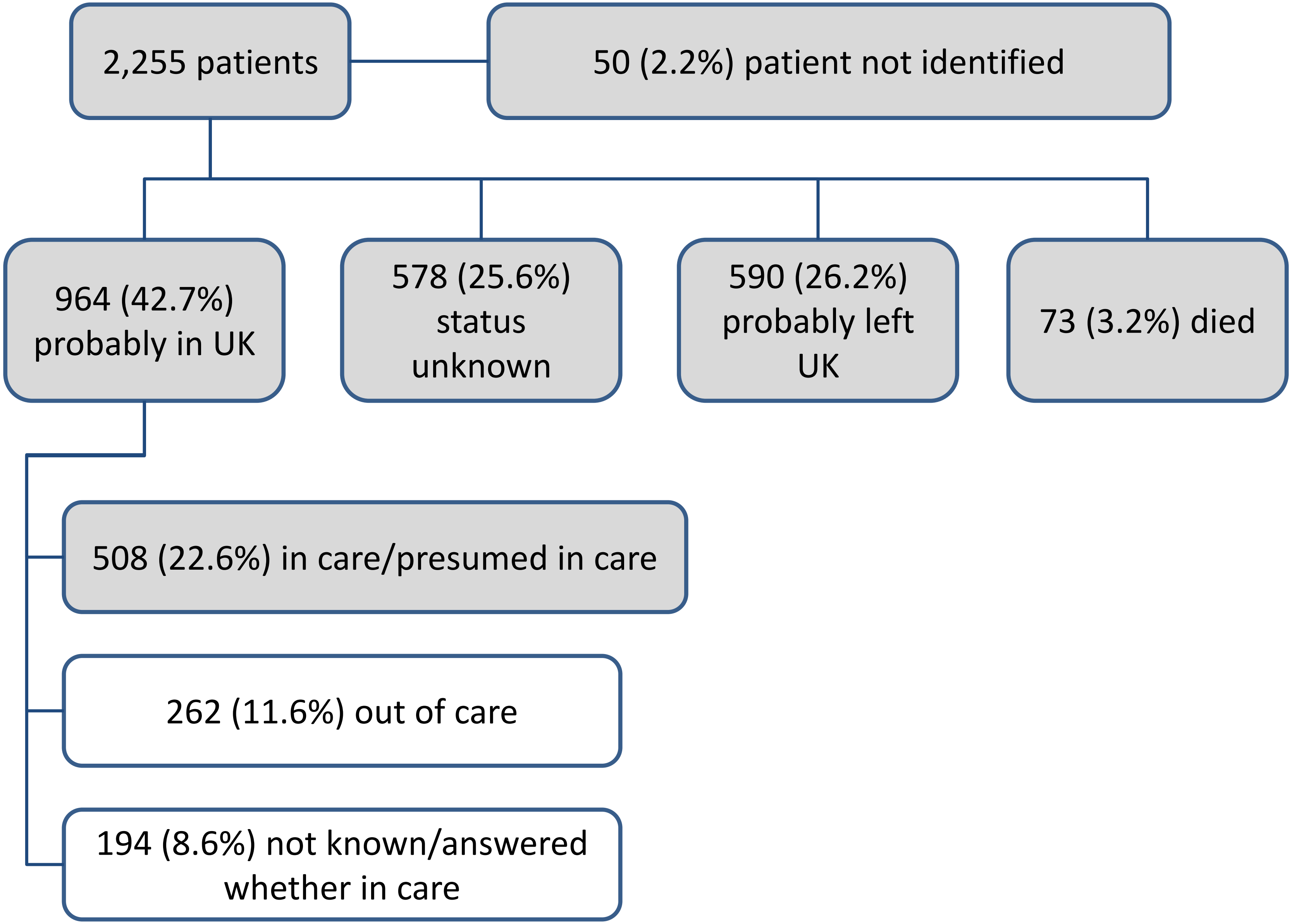
  "… informed of the positive result. He said he would attend a clinic in [place] as he was going to be [there]. [He later said he had] attended for confirmatory testing."

  "transfer letter done in 2010"

*Excluding patients from Scotland where linking was not done.

Patients remaining in the UK

Comparisons between patients not in care and those in care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Comparisons between patients in care and not in care

	Audited patients remaining in UK		SOPHID data	
	Out of care/not known	In or presumed in care	Patients in care	p
Total	456	508	68,398	
Under 40	245 (54)	232 (46)	28,413 (42)	<0.000001
Over 40	207 (45)	269 (53)	39,985 (58)	
Male	272 (60)	289 (57)	45,520 (67)	0.01
Female	175 (38)	194 (38)	22,878 (33)	
White	179 (39)	238 (47)	36,054 (53)	<0.000001
Black-African	214 (47)	207 (41)	23,607 (35)	

Figures shown are numbers (percentages). Totals do not add because not known/not answered data is not shown.
*New diagnoses rather than SOPHID data.

Comparisons, continued

	Audited patients remaining in UK		SOPHID data	
	Out of care/not known	In or presumed in care	Patients in care	p
Extended questionnaire total	**230**	**106**	68,398	
Diagnosed 2009-10 Diagnosed 2008 or before	79 (34) 133 (58)	24 (23) 73 (69)	10,791 (16) 52,680 (77)	<0.000001
ART naïve On ART when last seen Previously on ART	113 (49) 85 (37) 28 (12)	29 (27) 65 (61) 7 (7)	9,344 (14) 56,007 (82) 2,628 (4)	<0.000001
Declined ART Did not decline ART (during previous year)	30 (13) 183 (80)	4 (4) 92 (87)	n/a	
Last CD4 <200 cells/mm^3 Last CD4 >200 cells/mm^3	25 (11) 188 (82)	11 (10) 78 (74)	4,142 (6) 58,779 (86)	0.003
Nadir CD4 <200 cells/mm^3 Nadir CD4 >200 cells/mm^3	59 (26) 148 (64)	34 (32) 45 (42)		

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Comparisons, continued

Number (%) of patients (extended questionnaire)	Out of care/not known Total 230	In or presumed in care Total 106	p
Infrequent/irregular attendance	112 (49)	11 (10)	<0.000001
Good or fair attendance	96 (42)	79 (75)	
†Significant adherence concerns	27 (28)	8 (11)	0.01
†No or minor adherence concerns	59 (62)	54 (77)	
Affected by:			
Stigma	51 (22)	12 (11)	0.02
Financial issues, poverty	42 (18)	14 (13)	
Deprivation, housing problems	37 (16)	19 (18)	
Beliefs about HIV/ART	34 (14)	8 (8)	
Child or other carer responsibility	32 (14)	6 (6)	0.03
Uncertain immigration status	30 (13)	12 (11)	
Mental illness	30 (13)	12 (11)	
Alcohol/drug use/dependence	27 (12)	11 (10)	
Shift work/employment issues	21 (9)	5 (5)	
†Poor ART tolerability	20 (18)	6 (8)	
HIV symptoms	20 (9)	8 (8)	
Prison or detention	11 (5)	7 (7)	
Transition to adult care	3 (1)	1 (1)	

†ART-experienced patients only
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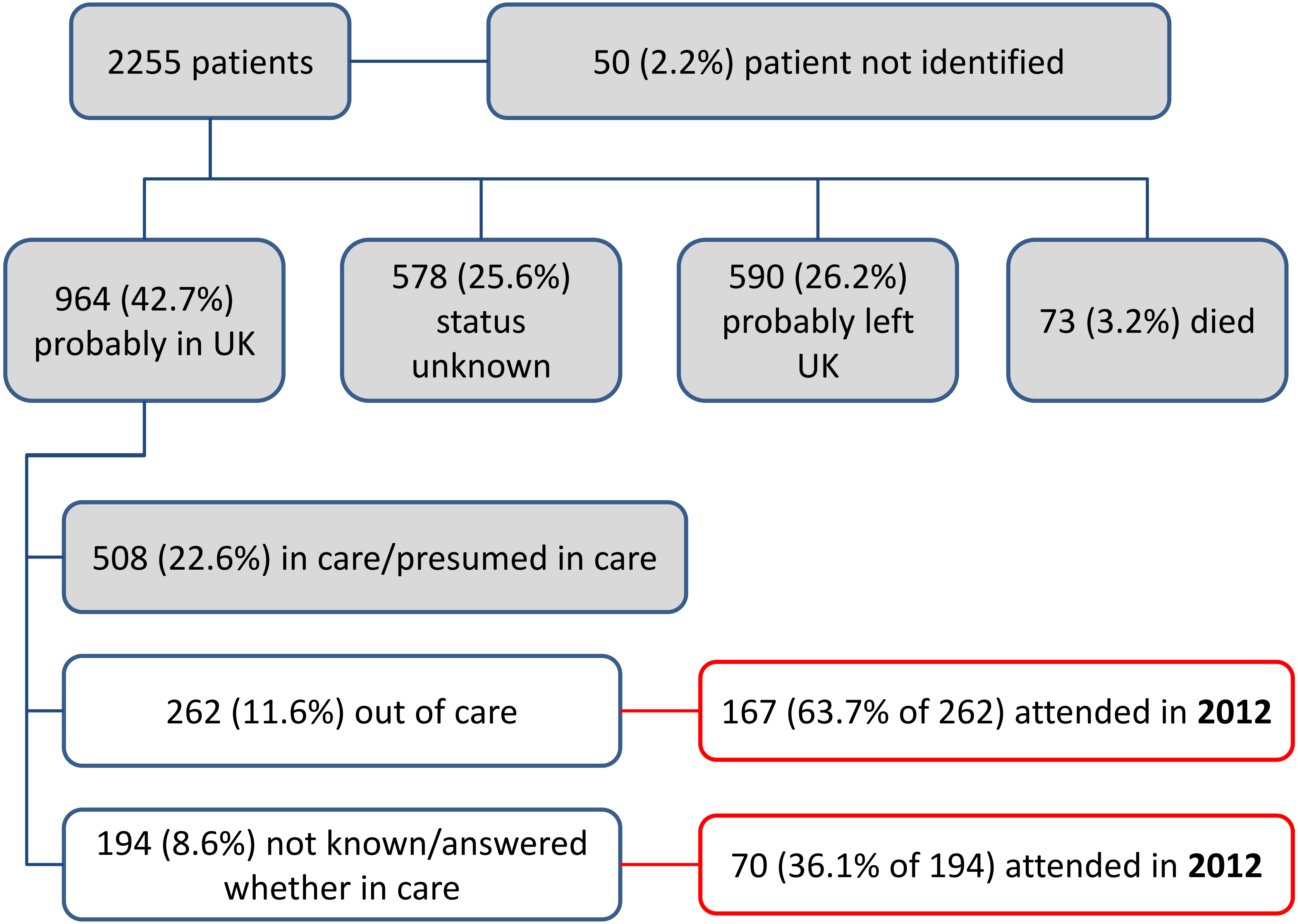
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262 (11.6%) out of care
167 (63.7% of 262) attended in **2012**
194 (8.6%) not known/answered whether in care
70 (36.1% of 194) attended in **2012**

Patients in the UK out of care/care status not known: consequences

	456 patients (262 out of care, 194 not known)	230 for whom long questionnaire completed
Re-attended 2012	237 (52.0%)	97 (42.2%)
Symptomatic on re-attendance		28 (12.2%)
In-patient admissions		9 (3.9%)
AIDS-defining conditions:		7 (3.0%):
TB		3 (2 inpatient, 1 pericardial)
PCP		2 (2 inpatient)
PML		1 (inpatient)
Cryptosporidial diarrhoea + weight loss		1 (inpatient)
Other inpatient admissions:		HIV nephropathy Ocular herpes zoster Headache/migraine, possible HIV leukencephalopathy

Patients in the UK out of care/not known: action taken

	456 patients (262 out of care, 194 not known)	230 for whom long questionnaire completed
GP details recorded	339 (74.3%)	175 (76.1%)
GP aware of HIV status		124 (53.9%)
GP contacted to encourage patient to attend		69 (30.0%)
Patient contact attempted to encourage to attend		183 (79.6%)

Site level data

Survey of policy and practice regarding retention in care

Standards of Care for People Living with HIV 2013

Standard 2:

Services must have mechanisms in place for those who miss appointments or transfer their care to another centre, to ensure people with HIV are retained in specialist care.

NB the *Standards* were published after the audit, so this was a baseline audit.

Policies on non-retention

134 sites completed the survey.

17 (13%) had a written and 106 (79%) an unwritten or informal policy on retention:

- 90 (67%) routinely discuss non-attenders in MDT, but 23 (17%) only for vulnerable patients.
- 40 (30%) have a written policy or template for information for patients transferring out.

Summing up

Limitations

By definition, information cannot be recorded for patients who are out of contact with care services.

Outcomes for some patients were more “best guess” than certainty.

It is not clear why more than 1 in 5 patients were thought to have remained in UK care without being linked in SOPHID.

Conclusions

Leaving the UK accounts for over a quarter of cases of apparent non-retention.

The outcome for many patients was unclear.

However, we estimate that at most 2.6% of people with HIV remained in the UK and out of care during 2011.

Conclusions (continued)

In univariate analysis, factors associated with disengagement from care (while remaining in UK) were:

- being younger and more recently diagnosed
- black-African ethnicity
- being ART naïve
- poor attendance
- poor adherence (if ART experienced).

Other factors may be relevant in individual cases but are unlikely to be useful as predictors.

Conclusions (continued)

Being out of care may have consequences in terms of disease progression, and risk of onward transmission.

Services actively attempted to re-engage patients who were recognised as being out of care, but GPs were often not involved even when aware of the patient’s HIV status.

Recommendations

Services should report all HIV care for surveillance purposes, regardless of the clinical setting in which the patient is seen.

HIV services should audit non-attendance at least annually and seek to re-engage patients where necessary.

The HPA should provide services with annual lists of patients not linked in SOPHID.

Recommendations

BHIVA should consider developing good practice guidance on:

- care transfers including verifying that the patient is attending the new provider
- action to take when patients do not attend as expected.

Further consideration should be given as to how to measure retention in care and to what extent this may be an indicator of service quality.

Acknowledgements

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2013 HIV Partner Notification Audit

Joint BASHH BHIVA national clinical audit

Aims:

- Record current practice, policy and outcomes of partner notification for HIV
- Work towards good practice guidance and outcomes standards.

Data collection April-June 2013 – invitations next week.

BASHH
National Audit Group

British HIV Association
BHIVA