

Contributions to UK Members of the Public, including Patients and Journalists 2022

Category	Number of Members of the Public/Journalists Contracted	Contracted Services Provided		Fees and Out of Pocket Expenses	Description of Support
Patients	2	Contracted Services	Fees	£90	HPP Patient Workshop: feedback on development of an App for HPP patients.
			Out of Pocket Expenses	£0	
Patients	1	Contracted Services	Fees	£150	Participation in the patient forum, providing insights and feedback relating to their disease journey
			Out of Pocket Expenses	£0	
Patients	3	Contracted Services	Fees	£375	Providing insights into their patient journey to diagnosis of thrombotic microangiopathy to HCPs
			Out of Pocket Expenses	£0	
Patients	6	Contracted Services	Fees	£2880	Patient Advisory board to capture the patient's perspective on living with rare conditions
			Out of Pocket Expenses	£0	
Patients	1	Contracted Services	Fees	£300	Providing insights from a patient's perspective relating to the journey, diagnosis and living with generalised Myasthenia gravis
			Out of Pocket Expenses	£0	
Patients	3	Contracted Services	Fees	£600	Participation in a workshop on the topic of aHUS in paediatrics
			Out of Pocket Expenses	£0	
Patients	2	Contracted Services	Fees	£600	Advisory services to research how pre-diagnosis PNH patients search online for information related to their symptoms.
			Out of Pocket Expenses	£0	
Patients	2	Contracted Services	Fees	£2000	Advisory services to gain a deep understanding of how PNH shapes everyday life for patients/families living with PNH.
			Out of Pocket Expenses	£0	
Members of the Public	1	Contracted Services	Fees	£405	Presentation on TMA in Paediatrics

			Out of Pocket Expenses	£0	
Members of the Public	1	Contracted Services	Fees	£4000	Preparing & chairing a roundtable discussion regarding the Innovative Medicines Fund Consultation. Review and comments on post-roundtable summary report.
			Out of Pocket Expenses	£0	
Members of the Public	1	Contracted Services	Fees	£1840	Consulting on Geographic Atrophy Literature Review Study
			Out of Pocket Expenses	£0	
Members of the Public	1	Contracted Services	Fees	£17460	Support with abstract submission and poster formatting for conferences, and drafting advisory board meeting minutes
			Out of Pocket Expenses	£0	

Reporting of Transfers of Value for UK Members of the Public, including Patients & Journalists Methodological Note for Reporting of 2022 Data in 2023

Introduction

Alexion is a member company of the Association of British Pharmaceutical Industry (ABPI). In accordance with the ABPI, companies must make publicly available annually details of the fees for certain contracted services paid to members of the UK public, including patients and journalists.

Alexion is committed to operating with integrity, accountability, and transparency, and to complying with all applicable laws and regulations. Alexion fully participates in the Association of British Pharmaceutical Industry's (ABPI) Disclosure UK initiative to increase transparency about its interactions with members of the UK public.

This note discloses the methodologies used by Alexion in preparing disclosures in compliance with ABPI Code of Practice.

ABPI Code Requirements

In accordance with Clause 30 of the ABPI Code:

30.1: Companies must make publicly available annually details of the fees for certain contracted services paid to members of the UK public, including patients and journalists. These services include speaking at meetings, assistance with training, writing articles and/or publications, participating in advisory boards, advising on the design etc of clinical trials and participating in market research where such participation involves remuneration and/or travel. The disclosure for contracted services provided by members of the public, in accordance with Clause 24, must include:

- the total number of members of the public, including patients and journalists contracted to perform services and the total amount paid per calendar year, and a description of the types of services provided that is sufficiently complete to enable the reader to understand the nature of the services provided without the necessity to divulge confidential information*
- companies should provide a breakdown of the total payments to each group of individuals, i.e. the public, patients, and journalists without the necessity to divulge confidential information*
- fees and expenses should be disclosed separately. Each company must include a note summarising the methodologies used by it in preparing the disclosures and identifying support and services provided.*

Transfer of Values

The disclosure template used by Alexion Pharma UK contains the following information:

- Category: Members of the Public, Patient or Journalist
- Number of Members of the Public/Journalists Contracted
- Fees and Out of Pocket Expenses for Contracted Services Provided
- Description of the Support

The Alexion, Members of the Public Disclosure Report will be disclosed on the UK Alexion company website.

The 2022 Members of the Public Disclosure Report covers ToVs made between 1st January 2022 and 31st December 2022.

Transfer of Value based on the Category

Patients: The Transfer of Value provided to patients is calculated by the global compliance team at Alexion and the amount is dependent on various criteria such as the type of engagement, the task at hand, the duration of the engagement and patient experience. The disclosed amounts are exclusive of VAT

Journalist: No Transfer of Value was made to a UK Journalist in the year 2022 on behalf of Alexion

Member of the Public: All Transfers of Value to Members of the Public are disclosed in British Pounds (GBP). Where Transfers of Values are made in another currency, the value of the transfer will be converted into GBP using the exchange rate on the date the transfer was made. Amounts disclosed in GBP may therefore vary slightly from the exact amount paid in the local currency. Alexion discloses the exact amount paid to the individual. This may include VAT, if included on the invoice.